Doctoral Thesis

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Guilt, Shame and Expressed Emotion in Mental Health Caregiving: Interventions and a Validated Scale

Doctorate in Clinical Psychology

Lancaster University

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2017 intake

Word Count

Section	Main text	Appendices (including references, figures and tables)	Total
Abstract	298	-	298
Literature Review	7,981	8,698	16,539
Empirical Paper	7,986	10,687	18,603
Critical Appraisal	3,987	4,420	8,303
Ethics Proposal	2,948	5,680	8,628
Total	23,200	29,485	52,371

Thesis Abstract

While caring for a loved one with a long-term mental health condition often brings fulfilment, it also carries the burden of complex emotions such as guilt and shame. These emotions can affect caregivers' well-being and relationships with those they support. Expressed Emotion (EE) examines how family members' attitudes and emotions impact the mental health outcomes of their loved ones, and this thesis explores the roles of guilt and shame within this context.

Section One presents a systematic literature review (SLR) that synthesises quantitative studies on interventions aimed at reducing guilt among caregivers. Due to the scarcity of interventions in mental health caregiving, the review incorporated studies from dementia caregiving literature to outline the current research landscape. Findings suggest that addressing dysfunctional thoughts may be a promising approach for mental health caregiving, however, the field lacks a standardised measure to assess this fully.

Section Two reports an empirical study focused on refining and validating the Care and Related Emotions (CARE) scale. Modifications were made based on cognitive interview feedback to ensure the scale effectively captures guilt, shame, and related emotions in mental health caregiving. Statistical analyses demonstrated strong content and structural validity, reliability, and predictive validity with EE components. While validated as a strong research tool, areas of further refinement are divergent validity and intra-rater reliability.

Section Three explores the implications of the research decisions and suggests future directions for the development of the CARE. By extending the focus on guilt and shame to incorporate the underlying attributions and beliefs that contribute to EE, the scale could provide a framework for clinicans to tailor interventions for caregivers.

In summary, this thesis contributes to the understanding of guilt and shame in caregiving, offering validated tools and highlighting areas for future research to enhance support for caregivers and their loved ones.

Declaration

The research presented in this thesis has been undertaken for the Doctorate in Clinical Psychology at the Division of Health Research, Lancaster University. The work presented through the thesis is the author's own, except where due reference is made. The work has not been submitted elsewhere for any other academic award.

Name: Laura Uhe Noir

Date: 27th August 2024

Acknowledgements

Firstly, I would like to express my deepest thanks to all the caregivers out there. There is immense honour in caregiving, yet for many, your sacrifices go unseen and the rewards aren’t always tangible. I hope this work contributes to improving the support you receive and helps keep you connected to what makes your role meaningful.

I would also like to express gratitude to my supervisor, Bill Sellwood. I have really enjoyed working with you. Your calm presence brought the best out in me, and your ideas, interest, and insight have been invaluable. To the friends I made during the doctorate, thank you for being accepting, supportive and encouraging. You know all too well what a journey this has been.

Thank you to my family. Matthew, we have always made a great team, and this latest challenge is proof of that. Your unwavering belief in me and your constant support have been my foundation. You’ve been my rock, nurturing and encouraging me every step of the way. I truly could not have done this without you. Audrey and Jerome, you have both given up the most for this work, so I hope it one day makes you proud. Audrey, you were so little when this started and now you are a big girl with a big beautiful heart who also wants to make the world a better place. I will forever cherish the artworks, cards and posies you leave on my desk. Jerome, your visits to my office with big smiles, stories of your day and warm hugs have seen me through some long nights. I am excited to move forward into the next chapter of our family story.

Finally, I would like to dedicate this work to my two grandmas. You both had to give up your ambitions of attending university because your working class families needed you to care for others. Your sacrifices have helped me find meaning in the challenges of navigating a career and motherhood. I have thought of you both often, reminding myself that while this is hard work, it is also a privilege. I hope this achievement shows how far our family has come.

Contents

Section One: Systematic Literature Review

Outcomes of Interventions in Reducing Guilt Among Family Carers of Adults with Psychological Health Needs: A Systematic Review of Quantitative Studies

Abstract: 245

Word count (excluding references, tables and appendices): 7981

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Declarations of interest: none

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[1] See Section One Appendix A for submission guidelines

Abstract

Guilt is a significant emotional challenge in dementia and mental health informal caregiving, recognised as a driver of expressed emotion. Reducing guilt may improve outcomes for both caregivers and care recipients, yet there is a lack of studies addressing this issue in mental health caregiving. This review aimed to evaluate current research on interventions that reduce guilt in family carers of adults with dementia or mental health needs. A secondary aim was to identify future research directions for adapting these interventions to a mental health caregiver context.

A PRISMA-adherent systematic review of peer-reviewed articles in English, using electronic databases (CINHAL, MEDLINE, PsycINFO, SOCindex) and hand searches, led to the inclusion of 13 peer-reviewed studies. All reported quantitative data on guilt scores, before and after an intervention, for adult family carers of relatives aged 18 years or older with dementia or other mental health needs. Guilt was a primary objective in four studies. Data were extracted, synthesised narratively and quality assessed.

The mean quality score (88%) reflected well-reported studies, though methodological rigour and generalisability varied by design. Seven RCTs strengthened the evidence base, and many interventions reduced guilt. However, small sample sizes, inconsistent methodologies, and unvalidated measures highlight the need for further high-quality research to enhance confidence in the findings.

Interventions that reappraise guilt related dysfunctional thoughts appear most promising in addressing caregiving guilt and warrant further exploration in the mental health caregiver context. Clinicians may also consider incorporating guilt-reduction strategies into broader psychotherapeutic support approaches.

Keywords: family caregivers, guilt interventions, family caregiver interventions, guilt measures, systematic review, quantitative studies

Outcomes of Interventions in Reducing Guilt Among Family Carers of Adults with Psychological Health Needs: A Systematic Review of Quantitative Studies

Mental health caregiving can be both a rewarding and demanding role. Family caregivers provide substantial unpaid labour, often at significant personal cost. The emotional and psychological impact on some caregivers has been well-documented, with stress, depression, and anxiety being common experiences (Koyanagi et al., 2018; Kuipers et al., 2010). There is a clear need to support relatives in their role, especially as their suffering can create a ripple effect that impacts the entire family system and exacerbate the challenges faced by their loved ones.

The way caregivers manage their own distress—whether through warmth, criticism, or over protection—can affect outcomes for care recipients and impact burden on the caregivers themselves (Kuipers et al., 2006; Raune et al., 2004). This phenomenon, known as expressed emotion (EE), reflects the strain within the family system, with high levels of EE indicating significant stress (Miklowitz, 2004). Initially identified in parents of adults with a diagnosis of schizophrenia in the 1960s (Brown et al., 1962), EE has since been extensively studied across various contexts, including bipolar disorder, eating difficulties (ED) (Hooley, 2007), and more recently, dementia care (Safavi et al., 2017).

The well-documented prevalence of EE has made it a key focus of mental health family interventions (Pharoah et al., 2010). However, there is an increasing demand for more specialised interventions aimed at addressing EE to enhance the wellbeing of both caregivers and their loved ones (Kuipers et al., 2010). Attribution Theory explains how caregivers' interpretations of their relative's suffering affect their emotional responses (Barrowclough & Hooley, 2003). If caregivers attribute causes to their own actions or shortcomings, they may feel emotions such as shame and guilt, which will influence their interactions with their loved one.

Guilt typically arises when individuals attribute a negative outcome to their own controllable actions or behaviours (Tracy & Robins, 2006). Taking responsibility for their actions usually motivates caregivers to make amends or change future behaviour to relieve associated discomfort. The close link between guilt and attributions of responsibility is thought to be the mechanism by which guilt can drive EE (Cherry et al., 2017). Shame, another self-conscious emotion, arises when one attributes a negative outcome to their own flaws or deficiencies and is associated with the critical comments (CC) component of EE. Caregiver interventions that focus on these emotions aim to modify the negative attributions of fault to potentially reduce EE behaviours and attitudes (Weisman & Suro, 2016).

Despite this understanding, the effectiveness of current interventions in alleviating shame and guilt is unclear. An earlier systematic review (Cherry et al., 2017) found only one mental health caregiver intervention specifically targeting these emotions (Weisman & Suro, 2016), which used an unreliable measure. In contrast, a growing body of literature on dementia caregiving focuses on addressing guilt, providing valuable insights that could inform interventions for mental health caregivers.

In dementia caregiving, guilt is recognised as a significant and persistent emotional challenge (Gallego-Alberto et al., 2022b; Martin et al., 2006). It can hinder self-care and reduce the willingness to seek social support (Losada et al., 2010). Unlike the focus on EE in other mental health contexts, the interest in guilt within dementia caregiving has primarily arisen from the literature’s historical focus on alleviating anxiety, depression and burden (Sallim et al., 2015). Recent reviews indicate the literature is moving towards targeting specific emotional outcomes, such as guilt, to enhance the efficacy of interventions (Cheng et al., 2020; Márquez-González et al., 2020).

As part of this development, guilt, as a symptom of depression (American Psychiatric Association, 2022), has been recognised as a factor that can influence the onset and maintenance of clinical needs in dementia caregivers (Roach et al., 2013). In addition, guilt is seen a more diverse and applicable intervention target because it is a prevalent experience amongst dementia caregivers, with some figures indicating up to 65% (Gonyea et al., 2008; Rosa et al., 2010). There is also the potential that, as outlined earlier, reducing guilt may decrease EE, which, in individuals with dementia, has been shown to improve mental health and reduce behaviours that challenge (Tan et al., 2021). Thus, alleviating guilt for caregivers could have a broad, long-lasting and positive impact on both the caregivers and those in their care.

However, to date, no reviews have systematically examined the available interventions that address guilt for caregivers. It remains unclear what interventions exist, their quality, overall effectiveness, or their methods to address guilt, which creates challenges in considering their potential relevance to a mental health context. Understanding the state of the research area could enhance both dementia and mental health literature by outlining ways in which future research can improve the quality of intervention studies in both fields. This knowledge could inform a framework of developments that could lead to the cross-application of effective interventions, providing clinicians with efficient ways to meet guidelines and support both caregivers and their loved ones.

Objective

To date, no systematic review has examined which interventions effectively reduce guilt in caregivers. This systematic literature review (SLR) aims to synthesise studies reporting quantitative outcomes on guilt from interventions for informal caregivers of adults with dementia or mental health needs. The review will evaluate current research and identify possible future research developments to strengthen the evidence base, with a particular focus on applications in the mental health caregiver context.

Method

This systematic review was conducted in accordance with the guidelines and criteria for systematic reviews stated in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Rethlefsen et al., 2021).

Initial Search

Following development of a Population, Intervention, Comparator, Outcome, Study design framework (PICOS), preliminary scoping searches were conducted on Google Scholar and Medline to evaluate the relevance of the review topic and identify existing literature reviews. These initial searches revealed no published systematic literature reviews in English assessing guilt interventions among informal carers of individuals with long-term psychological health needs. Due to the limited number of relevant reports found, a forward search using the caregiver guilt measure by Losada et al. (2010) on Google Scholar was subsequently conducted, which identified additional relevant studies. Many of these reports did not use the term ‘intervention’ in their titles, opting instead for terms such as ‘program’, ‘module’, or ‘training’. Additionally, some studies did not mention guilt in their abstracts but included these measures within their methods and results sections. Consequently, a comprehensive search of ‘all text’ sections was conducted using the search term ‘guilt’.

A Priori Inclusion and Exclusion Criteria

Inclusion:

- Published in peer reviewed journal in English up to 25th June 2024.
- Study sample must include family or other informal carers aged 18 years or older who provide care to relatives aged 18 years or older with mental health needs or dementia.
- Studies must report original data on a caregiver intervention and include a quantitative measure of guilt with before-and-after scores. Where possible, studies with comparison groups were included.
- Measurement must focus on self-conscious guilt related to psychosocial needs.

Exclusion:

- Unpublished, non-peer reviewed papers and studies not in English.
- To limit heterogeneity and maintain the focus on study aims, certain needs were excluded due to differences in caregiving challenges and support required. This study explicitly excludes caregivers of individuals who primarily identify as having needs related to physical health, learning needs, acquired brain injury, neurodiversity (such as autism spectrum conditions) or impulse control difficulties such as gambling or substance abuse. All other mental health needs were included.
- Studies that only report data from professional caregivers or those not identified as informal, unpaid carers.
- Studies that report only qualitative data on guilt, without quantitative outcome measurements.
- Studies that do not distinguish caregivers' outcomes from others i.e. they report quantitative data for caregivers and service users together, or staff and caregivers, etc.

Search Strategy

A search strategy was devised and reviewed by an information specialist, adhering to the Peer Review of Electronic Search Strategies (PRESS) checklist guidelines (McGowan et al., 2016). This strategy was tailored for each database, utilising specific subject terms, keywords, and MeSH titles to capture variations within three categories: (i) caregiver (ii) intervention (iii) guilt. The search syntax for each database is detailed in Table 1. Searches were conducted in EBSCO host across four databases (CINHAL, MEDLINE, PsycINFO, SOCindex), searched independently, from their inception until 24th June 2024. No limits, language or methodological filters were applied to minimise the risk of these excluding relevant studies. The search results were consolidated in Rayyan (Ouzzani et al., 2016), and duplicates were manually approved for removal. The titles and abstracts of the remaining papers were then screened.

The scoping search indicated it would be necessary to search for interventions that measured guilt as an outcome. Therefore, eligibility was assessed by reviewing the methods and results sections of the identified caregiver interventions. Appropriate full-text papers were subsequently accessed to determine suitability. Citation chaining of reference lists and pertinent systematic reviews (Cheng et al., 2020; Claxton et al., 2017; Groenvynck et al., 2022; Müller et al., 2017; Norder et al., 2022; Sampogna et al., 2023; Volpato et al., 2022; Zhai et al., 2023) were performed leading to the inclusion of three reports.

[Insert Table 1]

Quality Assessment

A validated tool designed for primary research across diverse study designs was selected to account for heterogeneity of the included studies. The Kmet et al. (2004) tool was chosen due to its high inter-rater reliability and clear scoring manual, enhancing transparency and reproducibility.

This quality assessment evaluates the extent to which the design, conduct, and analysis of studies minimise errors and biases and ensures reproducibility. Table 2 outlines the checklist which assesses 14 domains (Appendix A), focusing on the quality of the report in describing the research question or objectives, study design, sample characteristics, measures used and alignment between results and conclusions. It also evaluates processes such as randomisation and blinding, steps taken to control for confounding variables, sampling methods, analytical techniques, and the reporting of variance estimates. However, it primarily reflects the quality of study reporting rather than the methodological robustness or generalisability. It does not weight studies based on design strength, meaning well-reported pilot studies may score similarly to

Table 1

Search Syntax

String	Search Terms
String 1	TI (Caregivers+") OR ("Family Caregivers") OR Caregiver* OR "informal caregiver*" OR "informal carer*" OR Carer* OR "family carer*" OR "family caregiver*" OR “spouses” OR “spouse*” OR “partner*”)
String 2	AND TI ("Interventions" OR "Treatments" OR "Controlled Before-After Studies" OR “Randomi?ed Controlled Trials" OR "Intervention*" OR "Treatment*" OR "Management" OR "Control" OR "Therapy" OR "Facilitation" OR "RCT*" OR "randomi?ed control* trial" OR "randomi?ed" OR "pilot study" OR "Program" OR "Module" OR "Training" OR "Outcome*" OR "Teach*" OR "Project" OR "Trial" OR "Effectiveness" OR "Impact" OR "Evaluation" OR "Assessment" OR "Support* OR "Education" OR "Psychotherapeutic" OR "cognitive behavio?r* therapy" OR "emotional wellbeing" OR "cognitive behavio?r" OR "CBT" OR "cognitive behavio?r* therapy" OR "cognitive-behavio?r* group therapy" OR "cognitive behavio?ral factors" OR "Psychotherapy" OR "ACT" OR "Acceptance and Commitment Therapy" OR "CFT" OR "Compassion Focused Therapy" OR "DBT" OR "Dialectical Behavior Therapy" OR "Dialectical Behaviour Therapy" OR "MBCT" OR "Mindfulness-Based Cognitive Therapy" OR “mindfulness” OR "Psychoeducation" OR "Peer Support" OR "Group" OR "Psychosocial

	Intervention*" OR "Psychosocial" OR "Education" OR "Psychotherapeutic Techniques" OR Interpersonal Dynamics Analysis OR "Psychosocial Support" OR "Counse?ling" OR “counselling” OR “guidance” OR “mentor” OR "Guided" OR "Strategies" OR "Assistance" OR "Systems" OR "Facilitation" OR "Psychosocial Techniques" OR "Group Therapy")
String 3	AND ALL TEXT ("Guilt" OR "Shame" OR Guilt OR Shame OR "Self?conscious Emotions")

Note. TI refers to title

RCTs. Some criteria, such as selection bias and sample size, also require reviewer interpretation.

Each item is scored as ‘yes’ (2 points), ‘partial’ (1 point), or ‘no’ (0 points), with ‘N/A’ for non-applicable items. The total score was calculated by summing relevant items and dividing by the highest possible score, yielding a percentage score. For sample size, studies were scored one if there was fewer than 49 participants per condition, indicating insufficient power to detect a medium effect size using the standard benchmarks: medium effect size (Cohen's $d = 0.5$), a power of 0.80, and a significance level of 0.05. Studies were scored 0 if they were underpowered to detect large effect sizes (Cohen's $d > 1.0$).

The quality appraisal scores provided a structured comparison of study strengths and weaknesses, helping to contextualise findings across the research field. While no studies were excluded based on quality, findings must be interpreted with caution, particularly where small samples, inconsistent methodologies, or unvalidated measuresmay limit reliability. The main author (LN) independently assessed the included studies, and a colleague (SW) independently rated a subsample (n = 5) to evaluate the inter-rater appraisal reliability. Six discrepancies out of 70 were discussed and resolved, with agreed-upon by both raters scores.

Data Extraction

Data were extracted into a standardised table on Covidence (Veritas Health Innovation, 2024). For increased accuracy, quantitative outcome data were re-extracted after several days. Table 3 reported study and intervention characteristics, informed by the Template for Intervention Description and Replication (TIDieR; Hoffmann et al., 2014) checklist. Table 4 reports participant demographics and caregiving information. Table 5 details the guilt measures used across the studies, including their care context and guilt concept, range, and Cronbach’s Alpha (if available). Their peer-reviewed validation study is referenced and the factor structure outlined, otherwise the original study is italicised with sample items provided. Table 6 presents study outcomes (pre-test, post-test and any follow up scores) related to guilt, while Table 7 reports the calculated mean differences and effect sizes. Hedge's *g*, a variant of Cohen's *d* that corrects for bias in small or differing sample sizes, was used as it appropriate for this context and can contribute to meta-analyses (Lakens, 2013).

Results

Study Selection

The PRISMA flow diagram (Page et al., 2021) in Figure 1 outlines the systematic screening process. Initially, 1,268 records were identified. After removing duplicates, 997 titles and abstracts were screened. Of these, 81 caregiver interventions underwent full-text screening to determine if they used a guilt measure. Twenty-three studies were assessed for eligibility, resulting in the inclusion of 10. The 13 excluded reports were due to (i) only qualitative data reported; (ii) indistinguishable guilt scores (reported a total score of a multidimensional measure); (iii) non-psychological health context; and (iv) caregiver scores were indistinguishable from service users scores.

Citation and forward searching identified an additional three reports. There were 13 reports from 13 studies. Due to data/design heterogeneity, a narrative description is provided instead of a meta-analysis. See Figure 1 for an overview of the systematic screening process.

[Insert Figure 1]

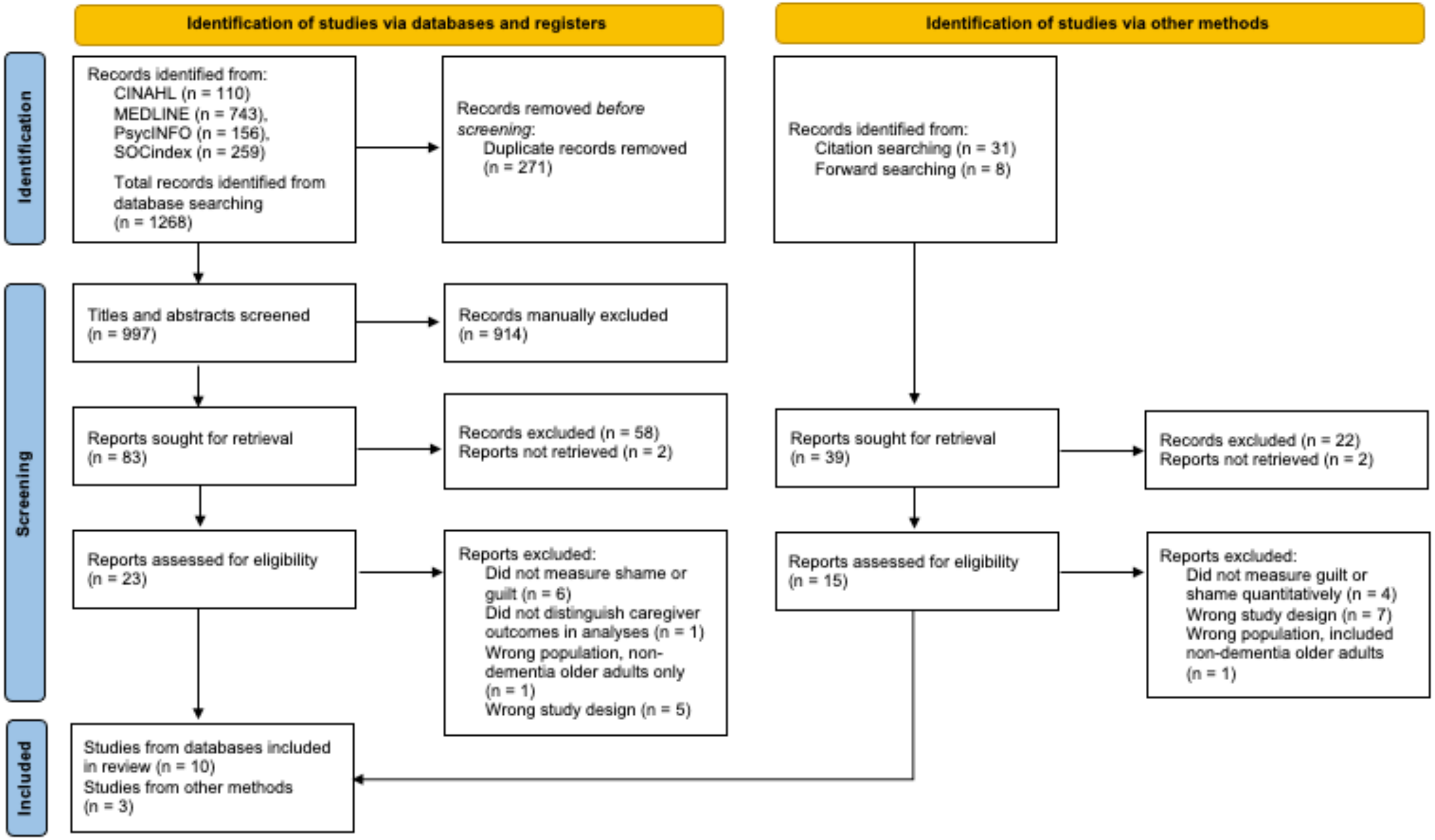
Quality Appraisal

Table 2 provides the quality assessment scores (Kmet et al., 2004) ranging from 73% (Mahmoudi et al., 2017) to 96% (Brooks et al., 2022, 2024; Romero-Moreno et al., 2022) with a mean score of 88%.

Focusing on both the report and the study, several issues were identified. Twelve studies had inadequate sample sizes and lacked power analyses, limiting evaluations of

Figure 1

PRISMA Flow Diagram of Study Selection



effectiveness. Additionally, concerns about the trustworthiness of the outcomes in four studies were raised due to the use of unvalidated guilt measures. The reporting of measures was occasionally inadequate, with important details such as score ranges and Cronbach's Alpha missing, further constraining the interpretation of findings. Poor reporting was also noted in descriptions of baseline characteristics, variance estimates, and randomisation procedures. Recruitment methods likely introduced self-selection bias, as most studies used opt-in procedures. However, two studies made deliberate attempts to recruit underrepresented groups, which helped mitigate some of the bias and enhance sample diversity.

Overall, there were eight high-quality studies (above 85%), and five moderate quality (70-85%). To improve rigour, studies require larger sample sizes, improved reporting of measures and baseline characteristics, and details of randomisation process in randomised controlled trials (RCTs). Despite small sample sizes raising concerns about Type I errors, no substantial bias was evident. As no studies were excluded based on quality, findings of this review must be interpreted with caution.

[Insert Table 2]

Study Characteristics

Study Designs

As presented in Table 3, various study designs evaluated the interventions. Seven studies used RCTs (Brooks et al., 2022, 2024; Davis et al., 2011; Hoyle et al., 2013; Quiles-Marcos et al., 2018; Romero-Moreno et al., 2022; Weisman & Suro, 2016) while two used quasi-experimental pretest-posttest designs (Mahmoudi et al., 2017; Paun et al., 2015), with four studies using an intervention for their comparison condition. An additional four studies conducted pretest-posttest pilot studies (Boise et al., 2005; Gallego-Alberto et al., 2021; Pépin & King, 2013; Stevens-Neck et al., 2023).

Table 2

Quality Appraisal (Kmet et al., 2004)

First Author, Year	1) Question / objective sufficiently described?	2) Study design evident and appropriate?	3) Method of subject/comparison group selection or source of information/input variables described and appropriate? for All outcomes	4) Subject (and comparison group, if applicable) characteristics sufficiently described? for All outcomes	5) If interventional and random allocation was possible, was it described? for All outcomes	6) If interventional and blinding of investigators was possible, was it reported? for All outcomes	7) If interventional and blinding of subjects was possible, was it reported?	8) Outcome and exposure measure(s) well defined and robust to measurement / misclassification bias? Means of assessment reported? for All outcomes	9) Sample size appropriate? for All outcomes	10) Analytic methods described/justified and appropriate?	11) Some estimate of variance is reported for the main results? for All outcomes	12) Controlled for confounding? for All outcomes	13) Results reported in sufficient detail? for All outcomes	14) Conclusions supported by the results?	Total Score (%)
Boise, 2005	2	2	2	2	N/A	N/A	N/A	1	2	2	2	1	2	2	20/22 91%
Brooks, 2022	2	2	2	2	2	2	N/A	2	1	2	2	2	2	2	25/26 96%
Brooks, 2024	2	2	2	2	2	2	N/A	2	1	2	2	2	2	2	25/26 96%

First Author, Year	1) Question / objective sufficiently described?	2) Study design evident and appropriate?	3) Method of subject/comparison group selection or source of information/input variables described and appropriate? for All outcomes	4) Subject (and comparison group, if applicable) characteristics sufficiently described? for All outcomes	5) If interventional and random allocation was possible, was it described? for All outcomes	6) If interventional and blinding of investigators was possible, was it reported? for All outcomes	7) If interventional and blinding of subjects was possible, was it reported?	8) Outcome and exposure measure(s) well defined and robust to measurement / misclassification bias? Means of assessment reported? for All outcomes	9) Sample size appropriate? for All outcomes	10) Analytic methods described/justified and appropriate?	11) Some estimate of variance is reported for the main results? for All outcomes	12) Controlled for confounding? for All outcomes	13) Results reported in sufficient detail? for All outcomes	14) Conclusions supported by the results?	Total Score (%)
Davis, 2011	2	2	2	2	2	2	N/A	1	1	2	2	2	2	2	24/26 92%
Gallego-Alberto, 2021	2	2	2	2	N/A	N/A	N/A	2	0	2	0	N/A	2	2	16/20 80%
Hoyle, 2013	2	2	2	2	1	N/A	N/A	2	1	1	2	2	1	2	20/24 83%
Mahmoudi, 2017	2	2	2	1	1	1	N/A	1	1	1	2	1	2	2	19/26 73%

First Author, Year	1) Question / objective sufficiently described?	2) Study design evident and appropriate?	3) Method of subject/comparison group selection or source of information/input variables described and appropriate? for All outcomes	4) Subject (and comparison group, if applicable) characteristics sufficiently described? for All outcomes	5) If interventional and random allocation was possible, was it described? for All outcomes	6) If interventional and blinding of investigators was possible, was it reported? for All outcomes	7) If interventional and blinding of subjects was possible, was it reported?	8) Outcome and exposure measure(s) well defined and robust to measurement / misclassification bias? Means of assessment reported? for All outcomes	9) Sample size appropriate? for All outcomes	10) Analytic methods described/justified and appropriate?	11) Some estimate of variance is reported for the main results? for All outcomes	12) Controlled for confounding? for All outcomes	13) Results reported in sufficient detail? for All outcomes	14) Conclusions supported by the results?	Total Score (%)
Pepin, 2013	2	2	2	2	N/A	N/A	N/A	2	0	2	2	1	2	1	18/22 82%
Paun, 2015	2	2	2	2	1	N/A	N/A	1	1	2	2	2	2	2	21/24 88%
Quiles-Marcos, 2018	2	2	2	2	2	2	N/A	2	1	2	2	1	2	2	24/26 92%
Romero-Moreno, 2022	2	2	2	2	2	N/A	N/A	2	1	2	2	2	2	2	23/24 96%

First Author, Year	1) Question / objective sufficiently described?	2) Study design evident and appropriate?	3) Method of subject/comparison group selection or source of information/input variables described and appropriate? for All outcomes	4) Subject (and comparison group, if applicable) characteristics sufficiently described? for All outcomes	5) If interventional and random allocation was possible, was it described? for All outcomes	6) If interventional and blinding of investigators was possible, was it reported? for All outcomes	7) If interventional and blinding of subjects was possible, was it reported?	8) Outcome and exposure measure(s) well defined and robust to measurement / misclassification bias? Means of assesment reported? for All outcomes	9) Sample size appropriate? for All outcomes	10) Analytic methods described/justified and appropriate?	11) Some estimate of variance is reported for the main results? for All outcomes	12) Controlled for confounding? for All outcomes	13) Results reported in sufficient detail? for All outcomes	14) Conclusions supported by the results?	Total Score (%)
Stevens-Neck, 2023	2	2	2	2	N/A	N/A	N/A	2	0	2	0	N/A	2	2	16/20 80%
Weisman de Mamani, 2016	2	2	2	2	2	2	N/A	1	1	2	2	2	2	2	24/26 93%

Research Areas and Countries

Nine studies focused on interventions for caregivers of individuals with dementia, with four supporting the transition to residential care. One study was in the context of psychosis, while three studies were related to ED. The USA and Australia featured prominently, with four studies each. Spain had three studies, the UK had two, and Iran had one study.

Sample Sizes

Boise et al. (2005) had a robust sample size of 257 participants. In contrast, the remaining 12 studies had fewer than 49 participants in each condition and were likely to lack sufficient power to evaluate outcomes. The pilot studies were particularly underpowered posing challenges to detect large effect sizes. Overall, the risk of inflated Type 1 error rates is high and results should be interpreted with caution.

Intervention Objectives

In four studies guilt was a primary objective (Gallego-Alberto et al., 2021; Mahmoudi et al., 2017; Romero-Moreno et al., 2022; Weisman and Suro, 2016), while guilt was a secondary objective in the remaining studies. All interventions aimed to improve caregiver outcomes by enhancing emotional management and coping skills. In the studies targeting guilt, reducing guilt was central to achieving these overarching goals.

[Insert Table 3]

Caregiver Characteristics

Table 4 presents caregiver demographics and caregiving information. In both dementia and mental health studies, the mean age of caregivers ranged from 50–60 years, except for one which focused on dementia spouses with a mean of 74 years (Brooks et al., 2022). In 10 studies, over two-thirds of participants were female. In two studies from an ED context, both mothers and fathers were recruited however female representation was still higher ranging from 59–61%.

Table 3

Study and Intervention Characteristics

			Intervention			Comparison		
First Author, Year (Location)	Research area (Funder)	Design (follow up)	Intervention protocol / Objectives / Provider	Format (*n*)	Session duration x frequency (total)	Comparison protocol / objectives	Format (*n*)	Duration x frequency
Boise, 2005 (USA)	Dementia (Meyer Memorial Trust)	Pretest-posttest pilot study (6 months)	The Powerful Tools for Caregiving program (Lorig et al., 1996) / Increase self-care, confidence, emotional management, decision-making, and communication / Trained peer caregivers	Group (257)	180min x 6 weekly (18 hours)	x	x	x
Brooks, 2022 (Australia)	Dementia (Dementia Australia Research)	RCT - pilot	Residential Care Transition Module (Gaugler et al., 2015) / coping, adjustment, and reduce burden / Trained Transition Counsellor	Phone (11)	60min x 6 fortnightly (6 hours)	One off printed information sheet	Paper (10)	x
Brooks, 2024 (Australia)	Dementia (Dementia Australia Research)	RCT	Residential Care Transition Module (Gaugler et al., 2015) / coping, adjustment, and reduce burden / Trained Transition Counsellor (psychologist)	Video (9)	60min x 6 fortnightly (6 hours)	One off check in call	Telephone (9)	x

			Intervention			Comparison		
First Author, Year (Location)	Research area (Funder)	Design (follow up)	Intervention protocol / Objectives / Provider	Format (*n*)	Duration x frequency	Comparison protocol / objectives	Format (*n*)	Duration x frequency
Davis, 2011 (USA)	Dementia (National Institute on Aging)	RCT	Family Intervention: Telephone Tracking-Nursing Home (Tremont et al., 2008) / cope with new placement burdens and stresses for caregivers / Trained Master's level therapist	Phone (24)	60min x 10 weekly calls + 90mins follow up (11.5 hours)	No contact	(22)	x
Gallego-Alberto, 2021 (Spain)	Dementia (Ministry of Economy)	Pretest-posttest pilot study	Guilt-focused intervention / dysfunctional beliefs (CBT) for caregivers through ACT, CFT and mindfulness / Psychologist	Group (4)	120min x 8 weekly (16 hours)	x	x	x
Hoyle, 2013 (Australia & UK)	Eating disorders	RCT (3 months)	Overcoming Anorexia Online (Grover et al., 2010) + additional guidance sessions / Systemic & CBT principles to reduce caregiver distress, EE and burden / Two trainee clinicians	Online + work-book and phone (19)	7 sessions + 7 x 20 min weekly phone calls (2.3 hours)	Overcoming Anorexia Online without extra guidance	Online + work-book (18)	7 sessions

			Intervention			Comparison		
First Author, Year (Location)	Research area (Funder)	Design (follow up)	Intervention protocol / Objectives / Provider	Format (*n*)	Duration x frequency	Comparison protocol / Objectives	Format (*n*)	Duration x frequency
Mahmoudi, 2017 (Iran)	Alzheimer’s	Quasi-experimental pretest-posttest (5 months)	Guilt focused CBT group therapy developed for study / dysfunctional guilt related beliefs to reduce adverse impact of caregiving / Trainee psychologist	Group (16)	180min x 14 weekly (42 hours)	Waitlist control	(16)	x
Paun, 2015 (USA)	Dementia (National Institute of Nursing Research)	Quasi-experimental pretest-posttest (6 months)	Chronic Grief Management Intervention (Paun & Farran, 2011) / teach communication, conflict resolutions and grief management skills / Trained advanced practice psychiatric nurses	Group (34)	60-90min x 12 weekly (12 to 18 hours)	Check in	Phone (49)	2 check in calls
Pepin, 2013 (Australia)	Eating disorders (Deakin University)	Pretest-posttest pilot study (8 weeks)	Maudsley Collaborative Care Skills Training Workshops (Sepulveda et al., 2008b) / CBT-group, support, improve coping, reduce burden / Trained psychologist	Group (15)	150 min x 6 weekly (15 hours)	x	x	x

			Intervention			Comparison		
First Author, Year (Location)	Research area (Funder)	Design (follow up)	Intervention protocol / Objectives / Provider	Format (*n*)	Duration x frequency	Comparison protocol / Objectives / Provider	Format (*n*)	Duration x frequency
Quiles-Marcos, 2018 (Spain)	Eating disorders (Ministry of Science and Innovation)	RCT (3 m)	Maudsley Collaborative Care Skills Training Workshops (Sepulveda et al, 2008b) / CBT-group, support, improve coping, reduce burden / Trained psychologist	Group (40) /	120min x 6 fortnightly + f/up (12 hours)	CBT Psycho-education (Fairburn et al., 2009) / CBT and Coping skills / Psychologist	Group (24)	120mins x 6 fortnight-ly + follow up
Romero-Moreno, 2022 (Spain)	Dementia (Ministry of Education, Culture and Sport)	RCT (3 m)	Guilt focused intervention (CBT, ACT & CFT; Gallego-Alberto et al., 2021): group format / Dysfunctional guilt beliefs for caregivers / Trained Clinical Psychologists	Group (23)	90min x 8 weekly + 3 f/up (16.5 hrs)	CBT for caregiving (Losada et al., 2006) / Dysfunctional thoughts / Trained Clinical Psychologists	Group (19)	90mins x 8 weekly + follow up
Stevens-Neck, 2023 (UK)	Dementia (Economic Social Research Council/ National institute for Health Research)	Pretest-posttest pilot study (3 m)	The Road Less Travelled program (Brotherhood et al., 2020) / Identify and process predeath grief / Dementia Care Nurse and caregiver peer	Online group (9)	120min x 6 fortnightly (12 hours)	x	x	x

			Intervention			Comparison		
First Author, Year (Location)	Research area (Funder)	Design (follow up)	Intervention protocol / Objectives / Provider	Format (*n*)	Duration x frequency	Comparison protocol / objectives	Format (*n*)	Duration x frequency
Weisman de Mamani, 2016 (USA)	Psychosis	RCT	Culturally Informed Therapy for Schizophrenia / Decrease burden, shame and guilt using CBT techniques / Clinical psychology trainees (doctoral level)	Face to face (64)	60min x 15 weeks (15 hours)	Psychoeducation (Falloon, Boyd, & McGill, 1984; Miklowitz & Goldstein, 1997) / destigmatise attribution of caregiver responsibility / Clinical psychology trainees (doctoral level)	Face to face (49)	3 sessions (T2 was at 15 weeks)

Only four studies reported sociodemographic information. Tertiary education was present in 27–68% of participants. Among dementia caregivers, about 67% were retired or not working, whereas 70–80% of caregivers in the ED studies were employed. Only four studies reported ethnicity. In three studies more than 80% of caregivers were white/Caucasian. In contrast, Weisman and Suro (2016) recruited a diverse sample, with 60% Hispanic and less than 30% white/Caucasian participants. Other minority group representation ranged from 1–9% per group and as only US studies reported this information, they were categorised as Latino, Asian/Pacific Islander, Native American, African American and 'other'.

Caregiving Information

Dementia caregivers were primarily spouses or offspring, while caregivers in ED and psychosis studies were mostly mothers and fathers. Living arrangements varied, with 37–92% living with the care recipient. Three studies (Boise et al., 2005; Brooks et al., 2022; Paun et al., 2015) focused on caregivers of individuals in residential care, where all care recipients resided in dementia care facilities.

Five studies did not report caregiving duration. Of the eight that did, the average length ranged from 3.5–5.5 years, except Paun et al. (2015), whose inclusion criteria required caregiving for less than one year. Only four studies provided information on time spent caregiving, however the use of different measurement methods has prevented meaningful synthesis.

[Insert Table 4]

Measurement

Guilt Measures

As presented in Table 5, nine studies used a guilt-specific measure. The peer-reviewed and validated Caregiver Guilt Questionnaire (CGQ: Losada et al., 2010) was utilised in six studies (Brooks et al., 2022; 2024; Gallego-Alberto et al., 2021; Mahmoudi et al., 2017;

Table 4

Caregiver Demographics and Caregiving Information

						Caregiver				
First author and year (location)	Caregiving context	Mean length of care (months)	Caregiver relationship	Living arrangement	Contact with SU	*n*	*M* age (*SD*)	% Female	Ethnicity	Employment status / Education level
Boise, 2005 (USA)	Dementia	x	36% spouse, 51% offspring, 13% other	55% live together, 13% SU in residential care	x	257	61 (26.9)	78	82% White, 8% Latino, 6% Asian/Pacific Islander, 3% Native American, 1% African American	33% FT/PT, 67% retired / 32%, 2nd, 68% 3rd
Brooks, 2022 (Australia)	Dementia	51	100% spouse	100% SU in residential care	50% visited daily	21	74.3 (10.9)	71	x	27% FT/PT, 73% retired / 73% 2nd, 27% 3rd
Brooks, 2024 (Australia)	Dementia	63	72% offspring, 28% spouse	44% lived with person, 55% lived separately	x	18	57.0 (12.4)	94	x	x
Davis, 2011 (USA)	Dementia	43	77.5% offspring	100% SU in residential care	x	53	57.3 (10.7)	83	x	x / M 15.7 SD 3.0 years
Gallego-Alberto, 2021 (Spain)	Dementia	54	50% spouse	x	10.25 hr p/w	4	67	50	x	x

						Caregiver				
First author and year (location)	Caregiving context	Mean length of care (months)	Caregiver relationship	Living arrangement	Contact with SU	*n*	*M* age (*SD*)	% Female	Ethnicity	Employment status / Education level
Hoyle, 2013 (Australia & UK)	Eating disorder	x	x	83% live together	x	37	x	89	x	x
Mahmoudi, 2017 (Iran)	Alzheimer's	x	x	x	x	32	x	100	x	x
Paun, 2015 (USA)	Dementia	7	17% spouse, 65% offspring, 18% other	100% SU in residential care	2.91 visits per week	83	60.7 (10.6)	88	91.2% Caucasian, 8.8% African American	X / M 15.7 SD 3.1 years
Pepin, 2013 (Australia)	Eating disorder	50	61% mothers, 22% fathers	x	x	18	51.3 (6.4)	61	x	x
Quiles-Marcos, 2018 (Spain)	Eating disorder	x	59% mother, 33% father, 5% sibling, 3% partner	92.30%	x	64	48.5 (7.5)	55	x	69% FT/PT, 8% unemp, 23% other / 68% 2nd, 32% 3rd
Romero-Moreno, 2022 (Spain)	Dementia	48	38% spouses	x	M 16.8 hr p/day	42	60.7 (13.3)	84	x	x

						Caregiver				
First author and year (location)	Caregiving context	Mean length of care (months)	Caregiver relationship	Living arrangement	Contact with SU	*n*	*M* age (*SD*)	% Female	Ethnicity	Employment status / Education level
Stevens-Neck, 2023 (UK)	Dementia	60	77% spouses, 22% offspring	55% live together, 44% SU in residential care	x	9	58 (10.3)	89	89% White British, 11% White Irish	x
Weisman de Mamani, 2016 (USA)	Psychosis	x	38% mother, 23% father, 8% partner, 20% sibling, 3% offspring, 9% other relative	37% live with SU	14% 50+ hr p/w, 21% 21-50 hr p/w, 27% < 20 hr p/w	113	53.8 (14.9)	86	60% Hispanic, 28.2% Caucasian, 8% African American, 3.8% other	x

Note. X = not reported; SU = service user; Hr p/day = hours per day; Hr p/w = hours per week; 2nd = secondary education or high school; 3rd = tertiary education.

Romero-Moreno et al., 2022; Stevens-Neck et al., 2023). Davis et al. (2011) employed the Caregiver Guilt Questionnaire for Nursing Home Placement (CGQ-NHP: Steadman-Wood et al., 2009), while Boise et al. (2005) used an adapted subscale from the Caregiver Guilt Scale (NDE-CGS: Kingsman, 1992). In addition to the CGQ, Mahmoudi et al. (2017) used a general Guilt Feelings Questionnaire (Alavi, 2006). Weisman and Suro (2016) developed a single-item guilt measure with a 7-point Likert scale.

The remaining four studies used guilt subscales from general caregiver measures. The three ED studies used the peer-reviewed and validated Eating Disorder Symptom Impact Scale (EDSIS: Sepulveda et al., 2008a), while Paun et al. (2015) utilised the guilt subscale of the Family Perception of Caregiving Role scale (FPCR-guilt: Maas et al., 2004).

[Insert Table 5]

Critical Appraisal of Guilt Measures

A strength of the research area is that all measures, except Mahmoudi and colleagues' (2017) supplementary measure, were specific to guilt about caregiving. Since guilt, as an action appraisal, is tied to specific contexts, this should be reflected in measures for accurate assessment (Tilghman-Osborne et al., 2012). To improve comparability, future studies should use the validated measure most relevant to their context. For instance, studies on guilt about residential care placement should use the validated version of the CGQ-NHP (GAP-Q: Davis et al., 2019) instead of the CGQ.

A strength of the dementia research is the wide use of the validated CGQ, a 22-item measure with a clinical cut off score for caregiving guilt. However, there is no equivalent measure for mental health caregiving. The EDSIS, while validated, measures guilt with only four items and is therefore unlikely to fully capture the complexity required to evaluate guilt-focused interventions (Mokkink et al., 2020; Tilghman-Osborne et al., 2012).

Table 5

Summary of Information about Guilt Measures

First author of study using measure	Guilt measure / guilt items	Validation study *(original study, if NV)*	Range (α)	Likert scale	Care context / Guilt concept	Factor structure or sample items
Brooks 2022, 2024; Gallego-Alberto; Mahmoudi[a]; Romero-Moreno; Stevens-Neck	CGQ/ 22 items	Losada et al., 2010	0 to 88 (.77–.91)	0 (never) to 4 (always or almost always)	Dementia / Guilt related dysfunctional thoughts	Five factors: "guilt about doing wrong to the care recipient," "guilt about failing to meet the challenges of caregiving," "guilt over experiencing negative emotions in relation to caregiving," "guilt about self-care," and "guilt about neglecting other relatives"
Hoyle, Pepin, Quiles-Marcos	EDSIS-guilt/ 5 items	Sepulveda et al., 2008; Carral-Fernández et al., 2013	0 to 20 (.78)	0 (never) to 4 (nearly always)	ED / Guilt, regrets, feeling responsible	Five items of guilt subscale: "Feeling that I have let her/him down" "Feeling that there could have been something that I should have done" "Thinking about where I went wrong" "Feeling that I should have noticed it before it became so bad" "Thinking that perhaps I was not strict enough"
Boise	NDE-CGS/ 4 items	*(Kingsman, 1992)*	0 to 12 (.73)	1 (strongly disagree) to 7 (strongly agree	Dementia / Guilty feelings of not doing enough	Sample item: "I felt that I have not done as much in the past as I could or should have for this person."

First author of study using measure	Guilt measure / guilt items	Validation study *(original study, if NV)*	Range (α)	Likert scale	Care context / guilt concept	Factor structure or sample items
Davis	CGQ-NHP/ 46 items	*(Steadman-Wood et al., 2009)*	0 to 184 (.84)	0 (never) to 4 (always)	Dementia / Guilt and self-blame about placing a relative in care home	Sample items: "I feel guilty when special family occasions come along," and "I feel that I was not a good caregiver because my loved one is not adjusting well."
Mahmoudi	Guilt Feelings Questionnaire / 38 items	*(Alavi et al., 2006)*[b]	38 to 125 (.75)	1 (strongly disagree) to 5 (strongly agree	No specific context / maladaptive and typical guilt	Two factors: maladaptive excessive feelings of guilt that are disproportionate to the situation; typical, less intense feelings of guilt that do not interfere with well-being
Paun	FPCR-guilt/ 5 items	*(Maas et al. 2004)* [b]	7 to 35 (.7–.84)	1 (strongly disagree) to 7 (strongly agree	Dementia / Exacerbators of grief in long-term care, including guilt and regret	Sample items of guilt subscale: feeling guilty about interactions with the resident, feeling that the caregiver isn't doing as much now for the resident as they could or should, feeling that the caregiver did not do as much in the past for the resident as they could or should
Weisman de Mamani	Guilt & self-blame / single item	*(developed for study)*	1 to 7	1 to 7	Psychosis / Guilt/self-blame about relative with psychosis	Single item: participants were asked to rate the degree to which having a relative with schizophrenia is a source of guilt/self-blame for them.

Note. NV = not validated.

[a] Mahmoudi used a 1 to 5 Likert scale, leading to a reported range of 34-110; [*b*] indicates original study was not retrievable.

Across the studies, all measures were self-report and as seven different measures were used, there are overall concerns about conceptual consistency as measure is each grounded in a different theoretical framework (Tilghman-Osborne et al., 2012). Additionally, five measures lacked accessible peer-reviewed validation studies, Mahmoudi et al. (2017) did not report translation procedures, several failed to report alpha coefficients, and several had very high variation in the *SD* relative to the *M*, casting doubt on their reliability and validity (Terwee et al., 2018). Given that only the CGQ and EDSIS are validated, findings from the four studies using unvalidated measures must be interpreted with caution.

In addition, some studies conflated guilt and shame. Widely accepted theories, such as those by Tangney and Dearing (2002) or Gilbert (2003) recognise guilt and shame as distinct emotions with different neurological pathways and intervention needs. Not making this distinction reduces confidence in their validity. Guilt and shame are also often conflated in everyday language, which creates problems when measures use the word 'guilt' in items (such as "I feel guilty about"). This probable confusion between terms undermines face validity (Terwee et al., 2018). In Weisman and Suro (2016) this was exacerbated by their use of a single-item measure. Single-item measures are also prone to measurement error and bias, have indeterminable internal consistency and construct validity. Consequently, this study is likely to have significant measurement bias, necessitating cautious interpretation of findings.

Reporting Guilt Outcomes

Table 6 presents the reported *M* and *SD* at baseline, post-intervention, and follow-up. In alignment with this review's aims to identify strategies to alleviate guilt, comparison interventions are also reported and synthesised. Inconsistencies in standard deviations score suggests Romero-Moreno et al. (2022) mistakenly reported standard error scores in some tables; however, only *SD* scores are reported here. Table 7 presents *M* differences between time points, effect sizes (Hedges' *g*) and significance levels of group differences between intervention and comparison groups, where available. The effect sizes are interpreted using Cohen's (1988) widely-used benchmarks. However, comparisons should be made only between methodologically related studies for an appropriate interpretation, such as Mahmoudi et al. (2017) with Romero-Moreno et al. (2022), or the ED studies (Thompson, 2007).

Considerable sample variability is reflected in the CGQ *M* scores, the very large effect sizes and large *SD*s relative to the *M*. When combined with small sample sizes, this variability can lead to a reduction in study power and an increased risk of Type I error rates (Hedges & Olkin, 1985). Due to the heterogeneity of measures and the absence of key statistical parameters (Cronbach's alpha scores, p-values or standard deviations) standardised *M* difference could not be calculated. Instead, effect sizes at follow-up are reported and represent within-group changes over time. Since this review focuses on identifying effective intervention elements rather than establishing an overall effect size, these limitations do not undermine the study's objectives. However, findings require careful interpretation in light of these and previously outlined limitations.

[Insert Table 6]

[Insert Table 7]

Interventions

Follow-up Periods

Eight studies featured follow-up periods, typically lasting three months (range: 2–6 months). Of these, seven showed a greater reduction in guilt at follow-up compared to immediately post-intervention. Although not always statistically significant, this trend suggests that guilt related to caregiving may require time to diminish.

Duration and Frequency and Format

Interventions ranged from six to 42 hours. Group sessions included two-hour sessions over six weeks and three-hour sessions over 14 weeks. Individual sessions lasted 60 minutes

Table 6

Reported Guilt Outcomes – Mean and Standard Deviation at Baseline, Post Intervention and Follow-Up

			Intervention						Comparison					
			Time 1		Time 2		Time 3		Time 1		Time 2		Time 3	
First Author, year	Guilt Measure (α)	Range	*M* *(SD)*	*n*	*M* *(SD)*	*n*	*M* *(SD)*	*n*	*M* *(SD)*	*n*	*M* *(SD)*	*n*	*M* *(SD)*	*n*
Brooks, 2022	CGQ (0.88)	0 to 88	22.8 (16.27)	11	21.8 (11.76)	10			27.63 (19.06)	10	23.13 (18.62)	9		
Brooks, 2024	CGQ (nr)	0 to 88	43.37 (nr)	9	27.63 (nr)	9			34.88 (nr)	9	32.75 (nr)	9		
Mahmoudi, 2017	**CGQ (0.77)**	**34 to 110**	**94.46** **(9.42)**	**16**	**57.31** **(8.74)**	**16**	**52.57** **(2.9)**	**16**	95.62 (6.6)	16	97.11 (7.25)	16	113.15 (6.9)	16
Mahmoudi, 2017	**Guilt Feelings (0.75)**	**38 to 125**	**114.57** **(18.08)**	**16**	**79.43** **(11.05)**	**16**			108.12 (12.75)	16	112.23 (11.43)	16		
Romero-Moreno, 2022	**CGQ (.91)**	**0 to 88**	**32.74** (9.84)	**23**	**19.25** (11.92)[a]	**23**	**18.34** (10.97)[a]	**23**	33.74 (13.61)	19	19.25 (10.71)[a]	19	24.34 (7.07)[a]	19
Stevens-Neck, 2023	CGQ (nr)	0 to 88	60.5 (nr)	8	59 (nr)	8	51 (nr)	8						
Paun, 2015	FPCR – guilt (.7–.84)	7 to 35	16.8 (5.3)	34	15.29 (5.4)	34	15.15 (4.95)	34	15.2 (4.7)	49	15.08 (4.15)	49	15.87 (4.49)	49

			Intervention						Comparison					
			Time 1		Time 2		Time 3		Time 1		Time 2		Time 3	
First Author, year	Guilt Measure (α)	Range	*M* *(SD)*	*n*	*M* *(SD)*	*n*	*M* *(SD)*	*n*	*M* *(SD)*	*n*	*M* *(SD)*	*n*	*M* *(SD)*	*n*
Boise, 2005	NDE-CGS (.73)	0 to 12	3.11 (2.5)	163	2.22 (1.8)	163	2.52 (2.1)	53						
Davis, 2011	CGQ-NHP (.84)	0 to 184	50.17 (30.03)	24	36.96 (31.4)	24			30.45 (23.71)	22	29.14 (25.91)	22		
Hoyle, 2013	EDSIS – guilt (.78)	0 to 20	9.36 (nr)	18	9.25 (nr)	13	9.23 (nr)	13	10.33 (nr)	18	8.39 (nr)	14	7.11 (nr)	16
Pepin, 2013	EDSIS - guilt	0 to 20	9 (5.51)	15	8.93 (5.56)	15	8.33 (5.37)	15						
Quiles Marcos, 2018	EDSIS – guilt (.62 -.85)	0 to 20	8.73 (5.61)	40	7.98 (4.21)	32	6.92 (5.43)	22	8.28 (5.37)	24	6.21 (5.11)	22	5.37 (5.15)	15
Weisman de Mamani, 2016	Single guilt item	1 to 7	3.11 (nr)	64	1.43 (nr)	64			3.07 (nr)	49	2.67 (nr)	49		

Note. Interventions where the primary objective was to alleviate guilt are marked as bold; Nr = not reported; For all measures, lower scores indicate lower levels of guilt.

[a] due to reporting error, only pooled SD was only available at some time points in this study.

Table 7

Guilt Outcomes for Interventions – Calculated Mean Difference, Effect Size and Significance of Difference Between or Within Groups

			Intervention			Comparison			
First author, year	Components to address guilt	Guilt measure/ range (α)	*n* at T3	T2-T1 *M* difference (ES)	T3-T1 *M* difference (ES)	*n* at T3	T2-T1 *M* difference (ES)	T3-T1 *M* difference (ES)	Effect summary/ Significance (between- or within-group)
Brooks, 2022	Personalised counselling via telephone - emotional support, stress management and relaxation exercises	CGQ/ 0 to 88 (.88)	10	-1 ns (0.03)	-	9	-4.50 ns (0.24)	-	No sig change within or b/w groups
Brooks, 2024	Personalised counselling via videoconferencing - emotional support, stress management and coping strategies.	CGQ/ 0 to 88 (nr)	9	-15.74* (nc)	-	9	-2.13 ns (nc)	-	sig within-group*
Gallego-Alberto, 2021	**Guilt focused group program - Tolerate and accept dysfunctional guilt beliefs (CBT) about caregiving though ACT/CFT exercises**	**CGQ/ 0 to 88 (nr)**	**4**	**-13.25* (nc)**	**-**		-	-	**sig within-group***
Mahmoudi, 2017	**Guilt focused group based CBT - Modifying dysfunctional guilt beliefs**	**CGQ/ 0 to 88 (.77)**	**16**	**-37.15*** (4.14)**	**-41.89*** (6.08)**	**16**	1.49 ns (0.21)	17.53 ns (2.6)	**Very large decrease/ sig b/w group***

			Intervention			Comparison			
First author, year	Components to address guilt	Guilt measure/ range (α)	*n* at T3	T2-T1 *M* difference (ES)	T3-T1 *M* difference (ES)	*n* at T3	T2-T1 *M* difference (ES)	T3-T1 *M* difference (ES)	Effect summary/ Significance (between- or within-group)
Mahmoudi, 2017	**As above**	**Guilt feelings/ 38 to 125 (.75)**	**16**	**-35.14*** (2.35)**	**-**	**16**	4.11 ns (0.34)	-	**Very large decrease/ sig b/w group*** **
Romero-Moreno, 2022	**Guilt focused group program - Tolerate and accept dysfunctional guilt beliefs (CBT) about caregiving though ACT/CFT exercises**	**CGQ/ 0 to 88 (.91)**	**23**	**-13.19** (4.76)**	**-13.50* (5.31)**		**See below**	**See below**	**Very large decrease/ sig within-group ** **
Romero-Moreno, 2022	Comparison condition - Tolerate and accept dysfunctional beliefs about caregiving using CBT group exercises (Losada et al., 2015)	CGQ/ 0 to 88 (.91)		See above	See above	19	-4.18ns (5.11)	-9.37* (3.07)	Very large decrease/ sig within-group**
Stevens-Neck, 2023	Group program - identifying strategies to manage pre-death grief and process denial, anger and guilt	CGQ/ 0 to 88 (nr)	9	-1.5 ns (nc)	-9.5 ns (nc)	x	x	x	No sig within-group change
Paun, 2015	Pre-death grief processing - recognising loses, processing reactions, acceptance and new attachments	FPCR – guilt/ 7 to 35 (.7–.84)	34	-1.51 ns (0.28)	-1.65* (0.32)	49	-0.12 ns (0.03)	-0.67 nr (0.15)	Small decrease/ sig b/w group*

			Intervention			Comparison			
First author, year	Components to address guilt	Guilt measure/ range (α)	*n* at T3	T2-T1 *M* difference (ES)	T3-T1 *M* difference (ES)	*n* at T3	T2-T1 *M* difference (ES)	T3-T1 *M* difference (ES)	Effect summary/ significance (between- or within-group)
Boise, 2005	Group workshop - session on learning from emotions and learning to deal with difficult feelings-anger, guilt, depression.	NDE-CGS/ 0 to 12 (.73)	53	-0.89*** (0.41)	-0.59* (.24)	x	x	x	Small decrease/ sig within-group*
Davis, 2011	Personalised counselling via telephone - psychoeducation, emotional support, coping strategies.	GAP-Q/ 0 to 184 (.84)	24	-13.21* (0.43)	x	22	-1.31 ns (-0.05)	x	Small decrease/ sig b/w group*
Hoyle, 2013	Online CBT based - psychoeducation, cognitive restructuring of dysfunctional thoughts, coping strategies. For intervention condition there was additional phone support. For the comparison condition there was no phone support.	EDSIS – guilt/ 0 to 20 (.78)	16	-0.11 nr (0.02)	-0.13 nr (0.03)	13	-1.94 nr (0.38)	-3.22 nr (0.63)	Comparison had medium decrease
Pepin, 2013	Online program - presumed - EE education, outline adverse impact of guilt driven actions, addressing thought distortions	EDSIS – guilt/ 0 to 20 (nr)	15	-0.07 ns (0.01)	-0.67 ns (0.12)	15	~~x~~	~~x~~	No sig within-group change

			Intervention			Comparison			
First author, year	Components to address guilt	Guilt measure/ range (α)	*n* at T3	T2-T1 *M* difference (ES)	T3-T1 *M* difference (ES)	*n* at T3	T2-T1 *M* difference (ES)	T3-T1 *M* difference (ES)	Effect summary/ significance (between- or within-group)
Quiles-Marcos, 2018	Online program - presumed - EE education, outline adverse impact of guilt driven actions, addressing thought distortions	EDSIS – guilt/ 0 to 20 (.62– 85)	22	-0.75 nr (0.15)	-1.81* (0.33)		See below	See below	Small decrease/ sig within-group*
Quiles-Marcos, 2018	Psychoeducation program on eating disorders, dysfunctional thoughts, behaviours, emotions and coping skills (Fairburn et al., 2009)	EDSIS – guilt/ 0 to 20 (.62–.85)		See above	See above	15	-2.07 nr (0.40)	-2.91** (0.55)	Medium decrease/ sig within-group**
Weisman de Mamani, 2016	**Guilt focused - personalised family, service user & caregiver CBT - thought monitoring, cognitive restructuring, behavioural activation, modify dysfunctional thoughts and attributions**	**Guilt/self-blame - single item 1 to 7**	64	**-1.68*** (nc)**	x	22	See below	x	**Sig within-group*** **
Weisman de Mamani, 2016	Information only psychoeducation – information about psychosis regarding causes, including genetics, neurochemistry and environment factors to alleviate guilt and shame	Guilt/self-blame - single item 1 to 7		See above	x	49	-0.40 ns (nc)	x	No sig within-group change

Note. Interventions where the primary objective was to alleviate guilt are marked as bold; To sufficiently provide information about the comparison interventions, they are reported in separate rows; X = no intervention and therefore no data; *nr* = not reported; n*c* = not calculable due to missing information (e.g. missing SD); *ns* = not significant; α = Cronbach's Alpha level, if reported; ES = Effect size, calculated as Hedges' *g* to account for differing sample sizes at time points; T1 = Baseline; T2 = End of treatment; T3 = Follow up, if reported; Sig = significant; Sig b/w group = significant difference between groups; Sig within-group = significant change within the same group over time; For all measures, lower scores indicate lower levels of guilt. Negative mean differences (T2–T1, T3–T1) reflect a reduction in guilt over time.

Effect summary refers to the magnitude of change in guilt, reported as Hedges' *g*, at T3. If T3 was not reported, the effect size at T2 was summarised. Effect sizes and their corresponding effect summary represent within-group change over time, not between-group differences. The significance of within-group differences is presented. If unavailable, between-group significance is reported, if available.

* $p < .05$

** $p < .01$

*** $p < .001$

over 6 to 15 weeks (Brooks et al., 2022; 2024; Weisman and Suro, 2016). Hoyle et al. (2013) offered 20 minutes of phone support but did not report the time involved for the online component. Formats included face-to-face and online group sessions, as well as individual sessions conducted in-person, by phone, or via video calls.

Guilt as a Primary Objective

For Dementia Caregivers. Three studies addressed guilt as a primary outcome. These group-based interventions used a Cognitive Behavioural Therapy (CBT) framework to address dysfunctional guilt thoughts related to caregiving. Mahmoudi et al. (2017) used master's level psychology trainees to deliver CBT-group therapy, teaching participants to challenge cognitive bias and problem solve. They used a waitlist control condition.

Gallego-Alberto et al. (2021) and Romero-Moreno et al. (2022) were the pilot and RCT, respectively, of an intervention which incorporated Acceptance and Commitment Therapy (ACT) and Compassion-Focused Therapy (CFT) strategies in the reappraisal of dysfunctional thoughts. These group sessions were delivered by qualified psychologists.

All three interventions demonstrated significant reductions in guilt, with Mahmoudi et al. (2017) and Romero-Moreno et al. (2022) showing very large effects; however only the latter was rated as high quality. Romero-Moreno's comparison intervention, focusing on dysfunctional thoughts about caregiving without a specific focus on guilt (Losada et al., 2006), also had a medium, significant decrease for guilt scores.

For Psychosis Caregivers. Guilt/self-blame was a primary outcome in Weisman and Suro (2016). This culturally informed psychosis intervention used tailored CBT techniques to modify maladaptive beliefs and improve outcomes for both caregivers and service users. It was delivered face-to-face by clinical psychology trainees. The comparison was three sessions of information-only psychoeducation for psychosis (Falloon et al., 1984; Miklowitz & Goldstein, 1997), which aimed to destigmatise caregiver attribution bias and also formed the psychoeducation component of the intervention condition. The guilt-focused intervention demonstrated significant reductions in guilt, but the information-only psychoeducation comparison did not. Although the study was of high quality, an effect size was not calculable and there was evidence of significant measurement bias due to the measure used.

Guilt as a Secondary Objective

Nine studies indirectly targeted guilt using various strategies such as identifying dysfunctional thoughts, enhancing emotional management and coping skills through counselling, multicomponent interventions or psychoeducation. They are categorised according to the descriptions recommended by Cheng and colleagues (2020).

Counselling Interventions for Dementia Caregivers. Brooks et al. (2022, 2024) and Davis et al. (2011) aimed to support caregivers during their relative's transition into dementia residential care. Trained clinicians delivered individualised telehealth counselling sessions to provide emotional support and develop coping skills. Brooks used the same protocol in both studies, one before placement (2024) and one after (2022), with a single check-in call as the comparison condition. Davis had a no-contact control group. Brooks (2024) and Davis showed significant reductions in guilt, while Brooks (2022) did not.

Multicomponent Interventions for Dementia Caregivers. Boise et al. (2005) also focused on dementia transition using trained caregiver peers to deliver multicomponent skills workshops, incorporating only one session on coping with emotions like guilt and anger. Paun et al. (2005) and Stevens-Neck et al. (2023) delivered multicomponent interventions for processing anticipatory-death grief in dementia caregivers, addressing grief-related emotions like guilt. While strategies were not reported, nurses delivered the interventions. Paun included a check-in call as a comparison. Boise and Paun focused on residential caregivers and showed small significant guilt reductions. Stevens-Neck, who included both residential and home caregivers, did not significantly lower guilt scores.

Multicomponent and Therapeutic Psychoeducation Interventions for ED Caregivers. Three interventions supported caregivers of relatives with ED. Pepin & King (2013) and Quiles-Marcos et al. (2018) used a CBT-group protocol for motivational interviewing to reduce distress, promote collaboration, and decrease EE. These workshops, delivered by clinical psychologists, did not appear to discuss guilt related thoughts or feelings and did not significantly reduce guilt scores. However, Quiles-Marcos' psychoeducation comparison condition, which were employed with CBT-psychotherapeutic skills (Fairburn et al., 2009) showed a significant medium decrease in guilt scores.

Hoyle and colleagues' (2013) intervention was an online psychoeducation program that used CBT-psychotherapeutic skills to teach participants to identify cognitive distortions, including those related to guilt. There were two conditions, one where trainee clinicians provided phone guidance on the intervention and one without the additional support. The group without additional phone guidance showed significant medium reductions in guilt while the group with phone support did not.

Strategies to Address Guilt – Notable Patterns

Many studies did not report specific techniques to improve guilt, and due to their heterogeneity and quality of the studies, specific conclusions about guilt are limited. However, effective interventions were noted to frequently employ a CBT-framework to target dysfunctional thoughts while interventions focused on developing skills to process emotional challenges, such as guilt, also demonstrate effectiveness. The four interventions that had guilt as a primary objective appeared to be the most effective, though these findings are preliminary due to biases present in three of the studies.

Discussion

As the first SLR of its kind, this is the first review to synthesise studies reporting quantitative outcomes on guilt from interventions for informal caregivers of adults with dementia or mental health needs. The aim was to identify future research directions to strengthen the evidence base of effective interventions and consider their application to a mental health caregiving context. While the available quantitative data suggests that various interventions can alleviate guilt, further research is necessary to enhance generalisability and fully understand these effects.

A systematic search identified 13 peer-reviewed studies reporting quantitative results. These studies were thoroughly described and quality appraised using a tool that accommodates diverse study designs, with a focus on internal reliability and comprehensive reporting as quality indicators. The *M* quality rating was high (88%), yet issues such as small sample sizes and the use of non-validated guilt measures were common. These factors raise the risk of Type II errors and positive bias (Cheng et al., 2020). A critical evaluation of guilt measures revealed that only one was sufficient for assessing guilt-focused interventions in a dementia setting, with no measure deemed appropriate for a mental health context. To improve overall rigour, studies should adopt more robust designs, larger sample sizes and standardised outcome measurements.

Considerable heterogeneity was observed across the studies. Caregiving responsibilities varied, with nine studies focusing on dementia, five of which focused on caregivers with relatives in residential care, and four studies were from a mental health context. The study designs comprised seven RCTs, four pilot pretest-post-test studies, and two quasi-experimental studies. Eight different measures of guilt were used. Including comparison interventions, a total of 16 interventions were identified, of which 13 were unique. Notably, four interventions had guilt as a primary objective.

Given the heterogeneity, a comprehensive narrative synthesis has been provided, encompassing study characteristics, participant demographics, quality appraisal, intervention features and strategies to reduce guilt, measures used to assess guilt, and quantitative findings on guilt reduction. The characteristics of the interventions, including components, content, dose, and mode of delivery, were systematically presented alongside study characteristics. Results were summarised using mean differences, effect sizes and *p*-values.

Collectively, the preliminary findings from this review indicate that interventions specifically targeting guilt in caregiving can effectively reduce this emotion, particularly those that focus on guilt-related dysfunctional thoughts. Broader interventions addressing non-specific dysfunctional thoughts or teaching emotional processing skills also contribute to guilt reduction, though to a lesser extent.

Intervention Outcomes and Theoretical Implications

The current evidence base is limited in drawing definitive conclusions about intervention effects on guilt. However, this comprehensive review has identified promising strategies and potential mechanisms for change that could guide hypotheses for future research. These strategies are outlined within relevant theoretical frameworks, summarising findings and considering their application to mental health caregiving settings.

Dysfunctional Thoughts

Preliminary findings suggest that psychosocial interventions can effectively reduce guilt in caregivers, with the targeting of dysfunctional thoughts a prominent strategy. All eight interventions that addressed these thoughts successfully reduced guilt. This aligns with the broader literature which recognises apated cognitions are a key mechanism of charge in most psychotherapy (Longmore & Worrell, 2007).

In the CB model, dysfunctional thoughts are irrational, negative, or distorted thinking patterns that exacerbate emotional distress and maladaptive behaviours. These thoughts often manifest as ‘cognitive distortions’, a term that describes catastrophising, overgeneralisation, or self-blaming responses that reinforce negative beliefs about oneself, others and the world

(Clark, 1995). These thoughts are rooted in beliefs based on cultural norms and internalised standards (Losada et al., 2011).

Typically, guilt arises when one perceives oneself to have not met one's personal expectations (Tangney & Dearing, 2002). When dysfunctional thoughts distort these internalised standards, guilt can become maladaptive for caregivers (Gallego-Alberto et al., 2021). In the mental health literature, attributional biases are believed to distort caregivers' beliefs about the causes of their relative's suffering. According to Attribution Theory when caregivers excessively attribute this suffering to their own perceived mistakes or inadequacies, they experience maladaptive levels of guilt or shame (Barrowclough & Hooley, 2003). Given the overlap between dysfunctional thoughts and attribution biases, future interventions should explore whether addressing guilt-related thoughts also reduces attribution biases. Reappraising these thoughts may help caregivers develop more balanced beliefs about the causes of their relative's suffering. As this may reduce both guilt and EE, improved outcomes could be seen across the broader family system.

Guilt as a Primary Objective

Three interventions used a CBT-framework to specifically address guilt-related dysfunctional thoughts. These interventions had a high dose, ranging from 16–42 hours, delivered face-to-face by highly trained clinicians, which likely contributed to the observed intervention effects. Two of the studies maintained the CBT-framework for the intervention, where CBT techniques such as cognitive restructuring were employed to address dysfunctional thoughts. These interventions significantly reduced guilt scores compared to comparison groups. However, Weisman and Suro (2016) used a measure with bias and an incalculable effect size, meanwhile the Mahmoudi et al. (2017) study was of moderate quality, suggesting overstated effects.

The third intervention, which incorporated ACT and CFT techniques to reappraise the dysfunctional thoughts, showed a very large, significant decrease in a high-quality RCT (Romero-Moreno et al., 2022). The pilot showed a significant decrease but no caclulable effect size and a very small sample size (Gallego-Alberto et al., 2021). Third-wave therapies, such as ACT and CFT, are derivatives of CBT that differ in strategies to address dysfunctional thoughts. While ACT focuses on acceptance of guilt-related thoughts (Hayes et al., 2012), CFT addresses self-criticism and promotes a self-compassionate voice (Gilbert, 2010).

The CBT interventions have the greatest potential to be effectively applied to more diverse contexts as CBT has a robust evidence base overall (David et al., 2018) and has been established as highly applicable, even in currently explored applications (Fordham et al., 2021). For third wave therapies, the evidence in caregiving is limited although studies show promising results, such as ACT's comparable effectiveness to CBT in reducing dysfunctional thoughts (Losada et al., 2015) and CFT's potential to enhance emotional regulation and well-being for both dementia and mental health caregivers (Hansen et al., 2022; Murfield et al., 2024).

Guilt as a Secondary Objective

Therapeutic Psychoeducation. Three unique psychoeducation programs reduced guilt by teaching caregivers to identify dysfunctional thoughts and understand stress triggers. Categorised as therapeutic-psychoeducation (Cheng et al., 2020), these programs taught CBT-techniques, such as cognitive restructuring and emotional regulation. Guilt was reduced in one moderate-quality study (Hoyle et al., 2013) and as the comparison intervention in two high-quality studies (Quilles-Marcos et al., 2018; Romero-Moreno et al., 2022). These findings suggest that integrating dysfunctional thoughts into therapeutic psychoeducation is effective. With recent reviews supporting therapeutic psychoeducation in both dementia and mental health caregivers (Cheng et al., 2020; Sampogna et al., 2023), there is scope to adapt the guilt-focused CBT-interventions for broader dissemination through psychoeducation.

Informational Psychoeducation. Informational psychoeducation is cost-effective and easily administered, but has only shown a small impact on mental health caregiver outcomes (Sin et al., 2017). This is possibly due to not addressing the burden of responsibility caregivers often feel (Barrowclough & Hooley, 2003). In this review, three psychoeducation programs aimed to reduce guilt-related attributions of responsibility by providing information on the aetiology of relevant mental health needs. Two programs reduced guilt scores, however they combined informational content with therapeutic-psychoeducation elements (as outlined above), which has obscured the impact of the informational component. Although the comparison condition in Weisman and Suro (2016) was an information-only psychoeducation program for psychosis, the study was limited by measurement bias (see earlier appraisal of guilt measures).

Given the theoretical link between attributions of responsibility, dysfunctional thoughts, and guilt outlined earlier, research should investigate whether informational psychoeducation can effectively alleviate guilt-related dysfunctional thoughts and attribution biases. Further research could explore if this leads to changes in EE.

Counselling Programs. Three high quality studies evaluated counselling programs during the transition of their loved one to a residential care facility. These interventions used the therapeutic relationship and emotional support to help caregivers reappraise their situations, process emotions and develop coping skills. The theoretical models underlying these programs share a focus on stressor appraisal (Gaugler & Kane, 2015; Lazarus & Folkman, 1984), aligning closely with the CBT concept of dysfunctional thoughts. Brooks et al. (2024) and Davis et al. (2011) showed significant decreases compared to comparison groups. Although

Brooks et al. (2022) did not impact guilt scores, psychosocial interventions generally have a positive impact on the emotional well-being of caregivers (Cheng et al., 2020).

Multicomponent Workshops. Three dementia studies utilised multicomponent workshops to help caregivers process or accept challenging emotions, including guilt. These interventions focused on anticipatory grief or transitioning to residential care, making them less directly applicable to a mental health context. The specific strategies for emotional processing were not detailed, but were assumed to be part of the approach. Two high-quality studies (Boise et al., 2005; Paun et al., 2015) demonstrated that multicomponent workshops teaching emotional processing skills can lead to small reductions in guilt. A moderate-quality pilot study of an online workshop (Stevens-Neck et al., 2023) did not find significant guilt reductions, likely due to the small sample size and lack of statistical power. Despite the mixed findings addressing guilt, multicomponent interventions are generally evidenced as effective for both dementia (Cheng et al., 2020) and mental health caregivers (Hansen et al., 2022).

Applications to Mental Health Caregivers

The available evidence suggests that targeting dysfunctional thoughts can alleviate guilt, making them a suitable focus for adapting guilt interventions to the mental health caregiver context. However, this mechanism cannot be fully evaluated for appropriateness with mental health caregivers until a validated measure specific to this context is available. Future research should prioritise the development of such a measure, which, based on the findings of this review, should focus on dysfunctional thoughts and beliefs. This measure could inform the development of interventions and explore whether reducing guilt also leads to decreases in expressed emotion.

Other Mechanisms of Change

For dementia research, the focus should be on identifying and evaluating the effectiveness of interventions for dementia caregivers. Future research needs to design experimental studies to establish mechanisms of change, with a priority on the strategies to address guilt-related dysfunctional thoughts. However, the effectiveness of guilt-focused interventions should investigate the impact of factors such as dosage, duration, and the quality of clinician training.

Two workshops included in the review demonstrated effectiveness when delivered by trained nurses and peers. With growing evidence supporting the use of paraprofessionals in delivering interventions (Cheng et al., 2020), further investigation into the impact of clinical expertise and paraprofessionals is warranted to drive wider dissemination.

Individualised approaches often leverage the therapeutic relationship to drive change, a dynamic that can also benefit face-to-face group interventions with peers (Romero-Moreno et al., 2022). With systematic reviews and meta-analyses showing mixed outcomes between individual and group-delivered programs for dementia caregivers (Cheng & Zhang, 2020; Frias et al., 2020), understanding the impact of the relationship in different formats could lead to enhanced cost-effectiveness of interventions.

With six studies using telehealth and growing evidence supporting technology-based interventions (Zhai et al., 2023), appropriate programs should be adapted for technological formats. CBT-therapeutic psychoeducation is highly suitable for online, self-help formats, though only one study implemented this approach (Hoyle et al., 2013). Technological adaptations are cost-effective and crucial for wider accessibility as caregivers often face access barriers to participation such as time constraints, inflexible schedules, guilt about leaving their relative, or living in rural areas (Brodaty et al., 2005; Gallego-Alberto et al., 2022a).

Few studies reported ethnicity information, and only one delivering a culturally sensitive intervention. The effectiveness of these adaptions on uptake, feasibility, relevancy, and participation has not been evaluated. Culturally adapted interventions are generally sparse

(Cheng et al., 2020), yet need to be prioritised to increase participation, effectiveness and social impact (NICE; National Institute for Health and Care Excellence, 2017).

Strengths and Limitations

As the first systematic review of its kind, this study followed PRISMA guidelines to gather evidence and provide an overview of interventions addressing guilt in caregivers, with a focus on their application to a mental health context.

A key limitation is that the exclusion criteria potentially limited the number of interventions that had guilt as a primary objective. While other contexts were excluded to limit heterogeneity and due to differences in caregiving responsibilities and dynamics, the number of guilt-focused interventions was limited. Additionally, limiting the review to peer-reviewed studies published in English may have excluded guilt-focused interventions, as three of the four identified were from non-English speaking countries. Efforts to mitigate this included designing a comprehensive search strategy with an Information Specialist, piloting the search, hand-searching and reviewing many full-text reports. Despite these efforts, some relevant interventions may have been overlooked.

This study employed a rigorous methodology, including quality assessment by two independent raters and data extraction duplicated by the main author to increase reliability. However, challenges such as small sample sizes and the inclusion of lower-quality studies were encountered. The broad inclusion criteria also led to significant heterogeneity. The decision to include any study measuring guilt required an all-text search, resulting in the inclusion of studies with a limited focus on guilt, which complicated identifying shared elements of effective interventions. Moreover, the inclusion criteria led to interventions focused on specific topics, such as anticipatory grief, adding heterogeneity. Including relatives of those in residential care also created more diversity in caregiving dynamics and the guilt experienced (Cheng et al., 2020; Davis et al., 2015).

These issues were compounded by heterogeneity in study designs, intervention aims, components, outcomes, study quality, intervention dose, delivery, and implementer qualifications, ultimately preventing a meta-analysis. The quality assessment process primarily reflected reporting quality rather than methodological rigour, meaning well-documented pilot studies may have scored similarly to RCTs. As a result, while studies were well-reported, their robustness varied, affecting confidence in the findings. In addition, the clinical strategies to address guilt were gathered from original reports, which provided limited information, then simplified to identify key characteristics. As a result, these strategies may not be comprehensively represented.

To mitigate these limitations and enhance generalisability to future meta-analyses, an unbiased Cohen's *d* was calculated as the standard measure of effect size. While appropriate here, especially given the constraints of missing information in the included studies, Cohen's *d* may overestimate within subject effects compared to its use in between-subject designs (Lakens, 2013).

In conclusion, the results of this review should be interpreted in the context of its limitations. While the analysis of findings fulfilled the aim of surveying the research area, the findings are based on key characteristics from a heterogeneous set of studies, many of which were underpowered. Consequently, the differences presented may not indicate true differences in impact. Clinicians and researchers should consider these factors when applying the review's findings to practice or future studies.

Clinical Implications

The broad approach of this review provides valuable insights for clinicians aiming to align with best practice guidelines to support caregivers (NICE, 2020). Although preliminary, the findings highlight effective strategies for alleviating guilt or incorporating a guilt focus into broader support strategies. However, clinical assessments remain crucial for guiding intervention choice, ensuring alignment with primary variables and characteristics suitable for the intervention (Cheng et al., 2020).

For caregivers with high levels of guilt or overprotective behaviours, interventions which address guilt-related thoughts and beliefs appear most effective. These can be delivered in group settings or through personalised approaches, often involving weekly sessions by experienced clinicians, lasting 60 to 180 minutes for 8–15 weeks.

For caregivers transitioning loved ones into residential care, counselling support has shown effectiveness in alleviating guilt. Individualised sessions can be delivered in telehealth appointments lasting around 60 minutes, scheduled every fortnight for six sessions or weekly for 10 weeks.

Services seeking to integrate guilt-related content into multicomponent interventions can use resource-conserving options like CBT-therapeutic psychoeducation sessions or workshops that develop skills to process difficult emotions. These can be delivered in groups, face-to-face or online, by facilitators with varied training backgrounds, usually running 60–180 minutes for 6–12 weeks.

Delivery through technological approaches, particularly the phone, seem to be as effective and are likely to improve access to caregivers who cannot attend face-to-face sessions due to geographical or caregiving constraints.

Future Research

This review identified numerous hypothesis-generating patterns in the appraisal of interventions and measures. However, with few interventions specifically addressing guilt, the research area appears to be emerging and before these patterns can be tested as hypotheses, research must first achieve a certain level of generalisability. This section outlines the necessary recommendations to improve generalisability and address the general bias in the research area.

The review revealed that interventions with transparent techniques, clear aims, and consistent measures had the strongest evidence base and replicability. Categorising interventions, standardising intervention protocols, making them widely available, and incorporating comparison conditions would enable replicability in RCTs. Long-term follow-ups are essential, as guilt reductions were often not immediately observable and are likely to yield more encouraging outcomes.

As discussed earlier, future studies should prioritise validated outcome measures to reduce bias and increase comparability. While dementia research benefits from the CGQ and transition-focused interventions can use the GAP-Q, the mental health field currently lacks a context-specific validated measure of caregiving guilt.

Efforts should focus on developing and validating a measure that comprehensively captures the dysfunctional thoughts, unique experiences, and relational dynamics of mental health caregivers across numerous items. Measures should be designed to capture guilt specifically, avoiding items that inadvertently assess shame as conflating these emotions undermines the validity of the findings. Adopting widely-accepted theoretical frameworks that differentiate between these emotions, such as Tangney and Dearing (2002), will enhance the generalisability and precision of interventions.

Future studies should report power calculations and ensure adequate sample sizes. Although recruiting caregivers is challenging, it is crucial to address systematic biases in recruitment, as convenience sampling through caregiver organizations may overlook those less likely to seek support, such as men (Galdas et al., 2005). Researchers should make intentional efforts to recruit more diverse samples, with ethnicity reported as a minimum standard.

Studies often failed to report caregivers' employment hours or perceived support, creating challenges to contextualise findings or for future studies to accommodate work and family responsibilities in line with NICE guidelines (NG150; 2020). Recruitment should intentionally focus on making adjustments for caregivers with minimal support, who are often the most in need, to avoid systematically excluding their needs and responses.

Enhanced recruitment methods, standardised intervention approaches, and standardised outcome measures are priorities of future research to improve the generalisability and effectiveness of interventions aimed at reducing guilt in caregivers. Addressing these recommendations, will facilitate a deeper evaluation of specific techniques or study characteristics, ultimately leading to better support and outcomes for caregivers.

Conclusion

This SLR has narratively synthesised quantitative outcomes on guilt from interventions for informal caregivers of adults with dementia or mental health needs, providing evidence of their impact on caregiver guilt. Based on the available evidence, interventions targeting guilt-related dysfunctional thoughts show promise, while broader approaches that teach thought reappraisal and emotional processing skills also show potential.

The evidence supports prioritising dysfunctional thoughts in the adaptation of guilt interventions to the mental health caregiver context. However, the review also highlights significant gaps in the current research, including the need for more rigorous methodologies, larger sample sizes, and the development of a validated guilt measure specific to mental health caregiving. Addressing these gaps will strengthen the evidence base for further development of guilt focused interventions and facilitate the cross-application of effective strategies between dementia and mental health caregiving. Future research should focus on whether these reductions also decrease expressed emotion, as this will ultimatley improve caregiver well-being and outcomes for care recipients.

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Appendix A

Family Process Author Guidelines

Aims and Scope

Family Process is an international, multidisciplinary, peer-reviewed journal committed to publishing original articles, including theory and practice, philosophical underpinnings, qualitative and quantitative clinical research, and training in couple and family therapy, family interaction, and family relationships with networks and larger systems.

Since its inception over four decades ago, Family Process has become a major resource for mental health and social service professionals who are seeking cutting edge research and clinical ideas about family and systems theory and practice.

- The editorial advisory board comprises outstanding thinkers, researchers and practitioners drawn from an international arena, reflecting our intention and capacity to publish articles with world-wide relevance.
- Articles are expected to be both scholarly and accessible, and written in jargon-free prose.
- The journal strives for a dynamic interaction between theory/practice and research, such that articles on theory and practice inform future research, and research articles contribute to the development of meaningful theory and practice.
- The Family Process Institute web site, www.familyprocess.org, promotes an open forum for interactive dialogue based on journal content.
- Guidelines for submissions to Family Process may be found by clicking on the 'For Authors' link on the left, as well as in every issue of the journal.

Journal Article Preparation

Important: the journal operates a double-anonymized peer review policy. Please anonymize your manuscript and prepare a separate title page containing author details.

Prepare your manuscript according to APA style, 7th edition. Author will prepare at least two files:

- A title page prepared according to APA style 7th ed.
- An anonymized manuscript. Family Process uses a double-anonymized peer review process. Please ensure that all identifying information such as author names and affiliations, acknowledgements or explicit mentions of author institution do not appear in the anonymized manuscript.

Your anonymized manuscript should include:

- A short informative title containing the major key words. The title should not contain abbreviations.
- Abstract of approximately 150-250 words in length. There are no subheadings in the abstract.
- Three to seven keywords.
- Main body. Please reference the Journal Article Reporting Standards in the APA 7th ed. manual for specific headers and organization.
- Your anonymized manuscript should be formatted according to APA 7th ed. style.

Please pay particular attention to these formatting issues:

- Electronic manuscripts must be double spaced in 12-point font throughout, including the abstract and references. Pages should be numbered consecutively with the title page as page one and include abstract, text, references, and visuals.

- Manuscripts should not exceed 7,000 words or 30 pages for original articles and 9,000 words and 35 pages for review articles including title page, abstract, text, references, tables, and figures.
- Do not underline for emphasis; use the italic font.
- Headings must be short. Three levels of headings are used within the text, as follows:
    - First level heading: Centered, Boldface, Uppercase and Lowercase Heading
    - Second level heading: Flush Left, Boldface, Uppercase and Lowercase Side Heading
    - Third level heading: Flush Left, Boldface, Italics, Uppercase and Lowercase Side Heading
- Tables and Figures — Limit the use of tables to data that correlate specifically to article content or communicate large amounts of data efficiently. Take care not to duplicate information from the text in the tables and vice versa. Tables and figures may be embedded in the text or may be submitted on a separate page with a separate title, and must be cited within the text with placement indicated. For figures, EPS, TIFF or PDF formatting must be used. Type title, legend, and notes for figures double-spaced on a separate page.

Reference Style

This journal uses APA 7th ed. reference style. Review your reference style guidelines prior to submission.

Figures and Supporting Information

Figures, supporting information, and appendices should be supplied as separate files. You should review the basic figure requirements for manuscripts for peer review, as well as the more detailed post-acceptance figure requirements.

Authors can place supplemental materials on the article page on the journal's website. To submit such materials, please upload them with the manuscript to ScholarOne using the tab Supporting Information with call-outs to the supporting information in the paper (e.g., Table S1). More complete instructions for supporting information can be found at Wiley's FAQs on supporting information.

Peer Review

This journal operates under a double-anonymized peer review model. Papers will only be sent to review if the Editor-in-Chief determines that the paper meets the appropriate quality and relevance requirements.

In-house submissions, i.e., papers authored by Editors or Editorial Board members of the title, will be sent to Editors unaffiliated with the author or institution and monitored carefully to ensure there is no peer review bias.

Wiley's policy on the confidentiality of the review process is available here.

This journal participates in Wiley's Transfer Desk Assistant program.

Guidelines on Publishing and Research Ethics in Journal Articles

The journal requires that you include in the manuscript details about IRB approval, ethical treatment of human and animal research participants, and gathering of informed consent, as appropriate. You will be expected to declare all conflicts of interest, or none, on submission. Please review Wiley's policies surrounding human studies, animal studies, clinical trial registration, biosecurity, and research reporting guidelines.

This journal follows the core practices of the Committee on Publication Ethics (COPE) and handles cases of research and publication misconduct accordingly (https://publicationethics.org/core-practices).

This journal uses iThenticate's CrossCheck software to detect instances of overlapping and similar text in submitted manuscripts. Read Wiley's Top 10 Publishing Ethics Tips for Authors and Wiley's Publication Ethics Guidelines.

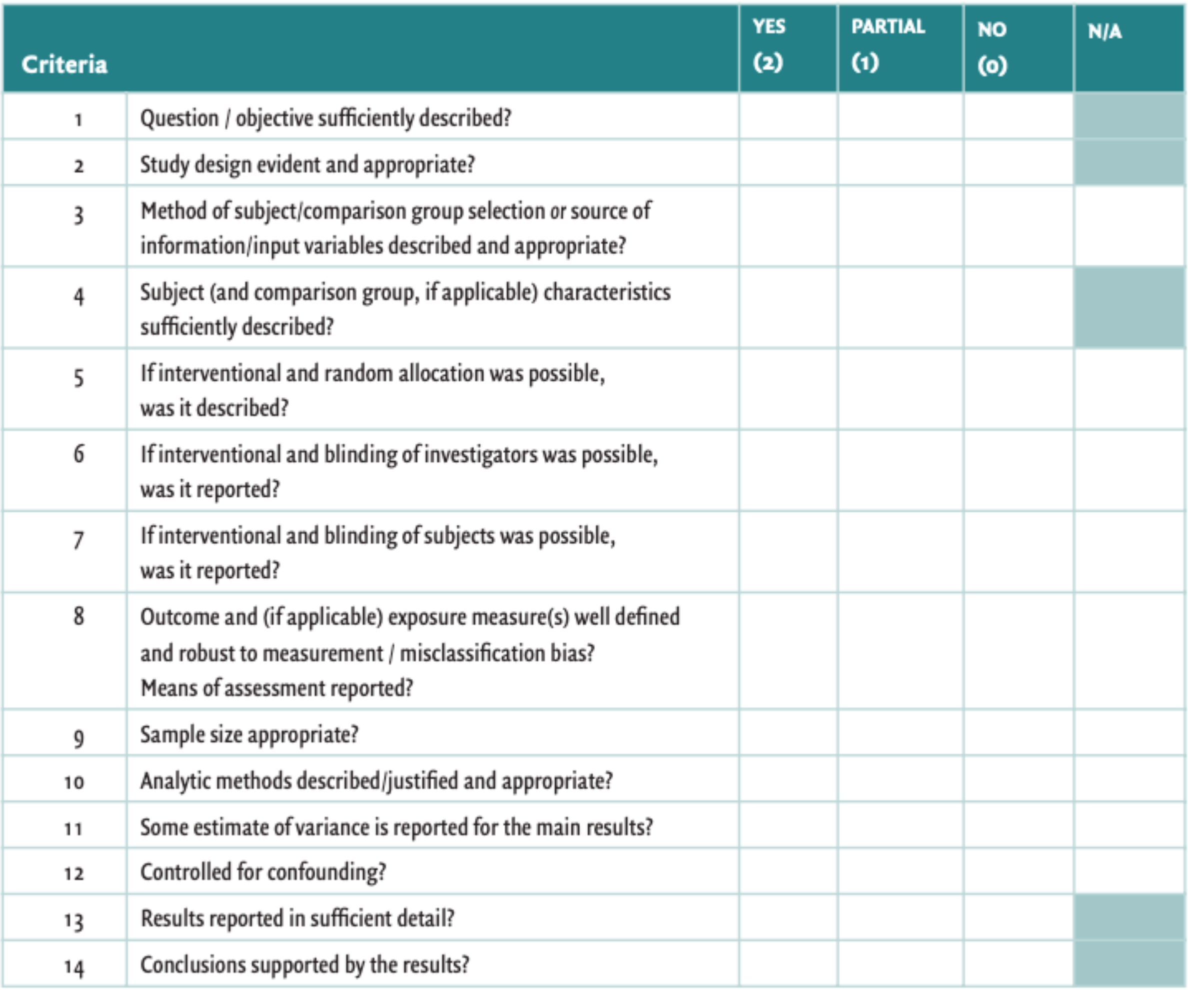
Article Types

Article Type	Description	Word Limit	Abstract / Structure	Other Requirements
Original Article	reports of new research findings or conceptual analyses that make a significant contribution to knowledge	7,000 limit (or 30 pages)	Yes, 150-250 words	Word limit includes title page, abstract, text, references, tables, and figures.
Review Article	critical reviews of the literature, including systematic reviews and meta-analyses	9,000 limit (or 35 pages)	Yes, 150-250 words	Word limit includes title page, abstract, text, references, tables, and figures.

Appendix B

Quality Appraisal Tool (Standard Quality Assessment criteria for Evaluating Primary Research Papers from a Variety of Fields (Kmet et al., 2004).

Table 1. Checklist for assessing the quality of quantitative studies



Criteria		YES (2)	PARTIAL (1)	NO (0)	N/A
1	Question / objective sufficiently described?				▨
2	Study design evident and appropriate?				▨
3	Method of subject/comparison group selection *or* source of information/input variables described and appropriate?				
4	Subject (and comparison group, if applicable) characteristics sufficiently described?				▨
5	If interventional and random allocation was possible, was it described?				
6	If interventional and blinding of investigators was possible, was it reported?				
7	If interventional and blinding of subjects was possible, was it reported?				
8	Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? Means of assessment reported?				
9	Sample size appropriate?				
10	Analytic methods described/justified and appropriate?				
11	Some estimate of variance is reported for the main results?				
12	Controlled for confounding?				
13	Results reported in sufficient detail?				▨
14	Conclusions supported by the results?				▨

Section Two: Empirical Paper

Development of a Guilt & Shame Measure in a Mental Health Caregiving Context

Word count (excluding references, tables and appendices): 7986 words

Abstract: 250 words

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Prepared in accordance with guidelines for authors for *Family Process*[2]

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Declarations of interest: none

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[2] See Section One Appendix A for submission guidelines

Abstract

Caring for loved ones with long-term mental health conditions imposes significant emotional burdens on informal carers, often leading to elevated stress and anxiety. Within this caregiving context, Expressed Emotion—particularly Emotional Overinvolvement and Critical Comments (CC)—is crucial for predicting outcomes in both mental health and medical conditions. The attributions underlying EE indicate emotions such as shame, guilt, and blame play a substantial role in these dynamics. However, traditional tools have struggled to assess these emotions adequately within caregiving settings.

The Care and Related Emotions Scale (CARE) was developed to fill this gap. This study aimed to refine and validate the CARE scale to ensure it accurately captures the specific emotional experiences of caregivers. Comprehensive cognitive interviews (n = 5) and extensive statistical analyses (n = 251) confirmed the scale's key measurement properties, including content and structural validity, internal consistency, test-retest reliability, and its convergent and predictive validity in relation to EE.

The study also identified intra-rater measurement error as an area for improvement, which could be addressed by updating the Likert scales. Future analyses should consider non-linear methods to better assess attributions such as blame. The strengths, limitations, and recommendations for further investigation are discussed, highlighting the scale's potential for improving caregiving outcomes.

The validation of the CARE scale positions it as a reliable and insightful tool with specific insights into the emotional dynamics of caregiving. It is a valuable resource for clinical applications and future research, poised to advance targeted interventions addressing the emotional challenges faced by caregivers.

Keywords: shame, guilt, mental health caregiving, informal carers, expressed emotion, emotional over-involvement, critical comments

Development of a Guilt & Shame Measure in a Mental Health Caregiving Context

Caring for a loved one with a long-term mental health condition is a profoundly challenging and emotionally demanding experience for informal carers. Balancing caregiving responsibilities with other life roles often results in significant stress and anxiety (Awad & Voruganti, 2008; Weiner, 1986). Such stress can negatively impact the quality of care provided, potentially leading to poorer outcomes for the care recipient. A critical concept in understanding these family dynamics is Expressed Emotion (EE), which refers to the emotional climate within the family, including how caregivers express their emotions and attitudes towards their loved ones. Introduced by Brown and Rutter (1966), EE is a robust predictor of outcomes across a range of mental health conditions, such as schizophrenia, bipolar disorder, and eating-related challenges (Hooley, 2007). Additionally, EE's influence extends to long-term medical conditions and other psychological health needs such as dementia (Safavi et al., 2017; Schulz & Martire, 2004; Wearden et al., 2000).

Two core components of EE are Emotional Over-Involvement (EOI) and Critical Comments (CC). EOI reflects overprotective or excessively self-sacrificing behaviours, while CC involves disapproving statements focused on the care recipient's actions or behaviour (Barrowclough & Hooley, 2003). Although self-sacrificing and protective behaviours can be beneficial, they can become intrusive and controlling when driven by an overwhelming sense of responsibility to alleviate the loved one's suffering (Vasconcelos E Sa et al., 2013; Vaughn & Leff, 1976). EE is typically assessed through the Camberwell Family Interview (CFI: (Vaughn & Leff, 1976), which evaluates observable behaviours and comments indicative of high or low EOI and CC. High levels of EE are strong predictors of symptom variation, relapse likelihood, and treatment outcomes (Hooley, 2007). Thus, understanding and intervening in EE is crucial for improving care outcomes. Carers exhibiting high EE often experience heightened anxiety and engage in more controlling behaviours than those with low EE (Kyriacou et al., 2008).

The Role of Shame and Guilt in Caregiving

The literature has focused on why some caregivers exhibit high levels of EOI or CC while others do not (Barrowclough & Hooley, 2003; Hooley, 2007). The transactional processes within EE often evoke deep-seated feelings of guilt and shame in carers (Hooley et al., 1995), making these emotions crucial in exploring the predictors of EE. Though guilt and shame are often conflated in common discourse, they are distinct self-conscious emotions with specific roles in caregiving.

Shame involves a pervasive negative self-evaluation, leading to feelings of being fundamentally flawed and fears of social rejection (Robins & Schriber, 2009). It evolved from the social threat system and can be internalised, where individuals see themselves as inherently bad ("I am bad"), or externalised, driven by fear of negative judgments from others ("Others see me as bad")(Gilbert, 1998; Norder et al., 2022). Conversely, guilt focuses on specific behaviours and their impacts on others, prompting reflections on actions and fostering reparative efforts such as apologising and making amends ("I did something bad"; (Robins & Schriber, 2009)). Generally viewed as adaptive, guilt evolved from the care system and encourages prosocial behaviours that maintain and restore relationships (Gilbert, 2003; Tangney & Dearing, 2002; Tangney & Tracy, 2012). However, operational definitions of these emotions vary, and their experiences are influenced by cultural, gender, and caregiving contexts (Tilghman-Osborne et al., 2010). To assess their unique variances with EE, this study adopts an adaptive definition of guilt to clearly distinguish it from shame.

Attribution Theory

Barrowclough and Hooley's seminal paper (Barrowclough & Hooley, 2003) established how attribution theory is relevant to EE. This framework can help differentiate these emotions by linking guilt to internal, unstable, and controllable attributions, while associating shame with internal, stable, and uncontrollable attributions (Tracy & Robins, 2006a). Within this framework, blame and externalisation are closely related to shame and guilt. Blame serves as a defensive mechanism from shame, shifting responsibility for distressing outcomes onto others (Brown, 2004; Tracy & Robins, 2006a). This can lead to anger (Tangney et al., 1996) and manifest as CC towards the perceived cause. Externalisation involves attributing negative events to uncontrollable external factors, thus avoiding personal accountability. In caregiving, this may present as a detached attitude. As attributions, blame and externalisation are not emotions themselves. They are, however, intricately linked cognitive strategies used to manage the challenging emotional experiences associated with caregiving, particularly shame.

Guilt, while typically considered adaptive, can become maladaptive and lead to EOI if caregivers magnify their role in their loved one's difficulties (Barrowclough & Hooley, 2003; Hatfield, 1981; Wasserman et al., 2012). This excessive sense of responsibility, termed in this paper ‘self-inflated responsibility,’ drives caregivers to engage in EOI, especially when they feel guilty or responsible for factors beyond their control or may arise when they have not adequately addressed perceived transgressions (Tangney & Tracy, 2012). Similarly, shame can lead to EOI when the pressure to meet high caregiving expectations drives caregivers to become overly involved, as an attempt to hide their perceived shortcomings in their caregiving role (Tangney & Tracy, 2012). CC, lacking an intention to repair, is less likely to be associated with guilt (Cherry et al., 2017).

The Need for Targeted Assessment Tools

Understanding how these emotions and attributions contribute to EE is crucial because EE consistently predicts relapse across various mental health conditions (Butzlaff & Hooley, 1998; Haidl et al., 2018; Weintraub et al., 2017). High EE not only impacts patients but also significantly affects carers, leading to increased anxiety, depression, and psychological distress (Jansen et al., 2015; Kuipers et al., 2010; Perlick et al., 2007). Furthermore, it is associated with diminished physical well-being, weakened immune function, and heightened mortality rates for caregivers (Dharmawardene et al., 2016). In response to these pressing needs, family-based interventions have been developed, in part, to reduce negative attributions in families, and have been shown in meta-analyses to be effective in reducing EE (Claxton et al., 2017).

Despite the importance of understanding EE, existing empirical evidence linking guilt, shame, and EE is limited, largely due to the limitations of current measurement scales (Cherry et al., 2017). Dispositional measures like the Test of Self-Conscious Affect (TOSCA; (Tangney, 1999), although widely used, may not fully capture the intense and complex emotions experienced in caregiving contexts (Tangney, 1996). Given that guilt involves the appraisal of specific behaviours or transgressions, its measurement must be specific to the caregiving context for accurate measurement (Tilghman-Osborne et al., 2010). While shame is pervasive and does not necessarily require a context-specific scale for measurement, traditional dispositional measures fail to account for the unique triggers of shame in caregiving. To illustrate, responses to minor oversights, like forgetting a lunch appointment (a scenario in TOSCA), are unlikely to provide meaningful insight into the profound emotional dynamics involved in caring for a loved one with long-term mental health needs. The relational and emotional complexity of caregiving demands a more tailored assessment approach to capture the depth and granularity of these emotional responses.

Advancing Measurement with CARE

To address these limitations, Keith (2011) adapted the TOSCA into the Care and Related Emotions Scale (CARE), to be a measure specifically designed to assess guilt, shame, blame, and externalisation in a psychosis caregiving context. The CARE scale has demonstrated deeper insights into how these emotions interact with EE compared to dispositional measures (Cherry et al., 2017; Messham, 2014). Furthermore, a later iteration of the CARE revealed that in the context of eating-related challenges, guilt, shame, and blame are related to EOI, with blame also predicting CC (Rothwell, 2023). However, progress has been stalled as the CARE has not been fully standardised or rigorously evaluated for reliability and validity.

Objectives of This Study

This study aims to refine and validate the most recent version of the CARE (Messham, 2014), ensuring it is a reliable and accurate tool that reflects the dominant constructs of shame and guilt experienced by informal mental health carers (Tangney, 1996). Expanding its application to mental health caregiving can improve understanding of the relationship between shame, guilt, and EE, aiding in the development and evaluation of targeted caregiver interventions (Cherry et al., 2017).

Method

Design

Ethical approval was granted by Lancaster University’s Faculty of Health and Medicine Research Ethics Committee (25/02/2021) (see Section Four: Ethics Proposal). The study adhered to the Standards for Educational and Psychological Testing (AERA et al., 1999) and the Consensus-Based Standards for the Selection of Health Measurement Instruments (COSMIN) guidelines (Mokkink et al., 2010a).

The study was conducted in three phases in line with COSMIN's structured approach (Prinsen et al., 2018): Phase 1 - content validity, Phase 2 - psychometric validation, and Phase 3 - test-retest reliability. The terminology and definitions of the relevant measurement properties used are outlined in Table 1, which also details the hypotheses and analysis plan.

[Insert Table 1]

Phase 1 - Content Validity

Design and Hypotheses

Content validity was assessed using the COSMIN methodology user manual (Mokkink, 2018), involving both professional and experiential experts (informal caregivers) to evaluate CARE-16. It was hypothesised modifications to the scale based on expert feedback and caregiver cognitive interviews would indicate that CARE items are relevant, comprehensible, and comprehensive, supporting content validity.

Table 1

International Consensus of Types of Reliability and Validity as Presented in COSMIN Guidelines (Mokkink et al., 2010; Mokkink et al., 2018a) with a Description of the Methodology and Associated Hypotheses.

COSMIN domain	Purpose	Method to address	Hypothesis
		Reliability	
Internal consistency	Interrelatedness between items that measure different aspects of the same construct	The statistical interrelatedness between the items of each subscale will be determined using Cronbach's α	Each CARE subscale is anticipated to achieve an acceptable level of Cronbach's α of between .70 and COSMIN's threshold of .95.
Reliability (test re-test)	Responses show reproducibility over time	To determine test-re-test reliability CARE was readministered to a subsample after two weeks. As the scale is ordinal, Spearman's rho assessed reproducibility across Time 1 and Time 2 scores.	Each CARE subscale or unidimensional structure is anticipated to achieve above COSMIN's acceptable minimum level of test-retest reliability of .70.
		To determine intra-rater reliability a weighted kappa, with a description of the weights included, was performed as this considered partial chance agreement that may occur for ordinal scales. ICC is only suitable for continuous scores.	COSMIN does not specify a strict minimum of weighted Kappa, however it is anticipated to reach above the minimum acceptable agreement of 0.40 for survey research (Landis & Koch, 1977).

COSMIN domain	Purpose	Method to address	Hypothesis
Measurement error	Changes in scores are not attributed to true differences.	To determine intra-rater agreement or measurement error for ordinal scores in a test-retest design, specific percentage agreement was calculated. Commonly used methods of Standard Error of Measurement, Smallest Detectable Change or Limits of Agreement were not suitable as they require continuous scores, and minimal important change requires a longitudinal study.	Specific percentage agreement would meet the acceptable threshold for survey research (≥ 60%), indicating adequate response consistency over time.
		Validity	
Content Validity			
Content validity	Considers the appropriateness of questions, the operational definition employed and incorporates face validity.	With the measurement objective of assessing the experiences of shame and guilt among caregivers of individuals with long-term mental health needs, a minimum of four professional experts and four individuals with lived experience will evaluate CARE.	Professional interviews will assess adherence to operational definitions as well as the relevancy and comprehensiveness of the items. Individuals with lived experience will pilot the scale and give cognitive interviews to determine if it is relevant, comprehensive and comprehensible for mental health carers.

COSMIN domain	Purpose	Method to address	Hypothesis
Construct Validity			
Structural validity	For reflective models, considers the degree to which existing subscales are factorially valid or reflect the theoretical dimensions of the construct.	As the first study to analyse the factor structure of CARE, exploratory factor analysis using principal components analysis (PCA) was performed to establish its dimensional structure. PCA was selected for its effectiveness in distinguishing highly correlated variables, such as shame and guilt, revealing underlying structures while streamlining variables without losing variability. Using a PCA subscales were then assessed for their unidimensionality.	The PCA will be exploratory, although due to previous poor performance (Messham, 2014), externalisation is not expected to be included in the factor structure. Final iterations of the guilt, blame and externalisation subscales are hypothesised to demonstrate unidimensionality, with their variance explained by a single factor. As shame is multidimensional, this subscale is expected to be explained by two factors: internalised shame and externalised shame.
Hypothesis Testing			
Convergent validity	How close the new scale is related to other measures of the same construct	As CARE is the first tool to assess self-conscious emotions in a care-giving context, a priori hypotheses were used to examine convergent and divergent properties of guilt and shame in caregiving in relation	Given the pervasive nature of shame across diverse situations, CARE shame is expected to demonstrate convergent validity properties through strong correlations with other shame measures. Thus, the shame subscale of CARE-11 will have

COSMIN domain	Purpose	Method to address	Hypothesis
Convergent validity, continued.		to other measures of shame and guilt (COSMIN, 2018a). It was important these measures were not explicit measures, did not conflate guilt and shame and that these measures were not tied to a specific context as this would prevent comparisons of guilt. Subsequently, CARE was compared with a measure of active guilt and shame using the State Guilt & Shame Scale and a measure of trait-like or proneness to guilt and shame, using the gold standard Test of Self Conscious Affect-3 (TOSCA-3). Spearman’s rho was used as it is appropriate for ordinal data.	a correlation with the shame subscales of TOSCA-3 and SSGS above >.50. Very strong correlations, above >.70, are not expected as this would indicate an overlap between the measures and a lack of specificity of the CARE.
Discriminant validity	Ability to distinguish between similar but distinct constructs	As above.	Given the context-specific nature of guilt, CARE guilt will show divergent validity properties through weak correlations with other guilt measures. Thus, the guilt subscale of CARE-11 will have correlations with TOSCA-3 and SSGS <.30

COSMIN domain	Purpose	Method to address	Hypothesis
Cross-cultural validity	How adequately a translated scale reflects the original version	The scale was not translated however, demographics are reported in results.	
		Criterion Validity	
Predictive Validity	Ability to predict the outcome of another measure.	Since the CARE scale is the first tool to assess self-conscious emotions in a care-giving context, obtaining evidence of criterion validity is challenging due to the lack of an established "gold standard" measure. Therefore, a priori hypotheses were used to examine the predictive properties of guilt and shame in caregiving in relation to the closely related concept, EE. Subsequently, it is more accurate to consider this as a measure of construct validity than criterion validity, and it will be positioned accordingly in the results. Correlations between the CARE and the Family Questionnaire (FQ), a valid and reliable measure of EE, were examined to assess predictive properties.	Correlations between the CARE and the Family Questionnaire (FQ), a valid and reliable measure of EE, were examined to assess predictive properties. The focus is on predictive properties as the CARE measures guilt and shame in caregiving, which are thought to influence EE and not expected to directly predict EE. Higher levels of guilt and shame are logically associated with higher EE, thus (.30-.50) strong associations will indicate predictive validity properties. As guilt is not related to CC, it is expected to show a weak or negligible relationship (<.30). Based on Messham’s (2014) previous research, correlations between shame and guilt with

COSMIN domain	Purpose	Method to address	Hypothesis
Predictive validity, continued.		The focus is on predictive properties as the CARE measures guilt and shame in caregiving, which are thought to influence EE, though are not expected to directly predict EE. Higher levels of guilt and shame are logically associated with higher EE, thus high associations will indicate predictive validity properties. Spearman's rho was used as it is appropriate for ordinal data.	EOI will be >.3 to <.7 and with blame will be <.3. For CC, correlations with shame and blame will be >.3 to <.7 and with guilt will be <.3. Correlations will not be high (>.7) as CARE is not expected to directly predict EE.
Responsiveness			
Responsiveness	Ability of the scale to detect change over time	Requires longitudinal design which was beyond the scope of this study	
Interpretability			
Interpretability	Clinical meaning that can be inferred from scores	Interpreting minimal change in scores requires a longitudinal study, beyond the scope of this study.	

Participants and Recruitment

Professionals. Four clinical psychologists, with at least four years of post-qualification expertise in shame, guilt, and long-term mental health care, volunteered in response to invitations from the research team’s network at the Faculty of Health and Medicine at Lancaster University and services in Northwest England.

Experiential Experts. Five adults providing informal care for loved ones with long-term mental health needs self-selected for involvement in response to invitations sent via mental health caregiver groups, social media, and third sector newsletters. Prior to the interviews, participants were presented with a participant information sheet and gave verbal consent to participate.

Materials

CARE-16 Scale. CARE-16 measures emotional responses of informal caregivers to hypothetical scenarios that may be encountered when caring for a loved one experiencing long-term mental health needs. At this phase of the study, there were 16 hypothetical scenarios measuring the responses guilt, shame, blame and externalisation (Messham, 2014; see also Section Four Appendix 9).

Further Development of the CARE-16. Interviews with professionals aimed to evaluate the relevance and comprehensibility of CARE-16 (Messham, 2014), focusing on the appropriateness of operational definitions, recall period, and the comprehensiveness of instructions and item responses. Questions included, “Is this scenario relevant to informal mental health carers?”, “Does this response align with the operational definition?”, and “Are there missing concepts?”. Each professional was consulted individually via Microsoft Teams for 60 minutes, with sessions recorded and live notes taken. Changes were iteratively tested, and consensus was determined when few or no further modifications were proposed, resulting in the updated CARE-12.

CARE-12 Scale. Experiential experts piloted CARE-12 through individual cognitive interviews, each lasting 60-90 minutes via Microsoft Teams. A semi-structured approach (Willis, 2004), was used to explore the clarity, relevance and comprehensiveness instructions, scenarios, responses and recall periods. For example, a meaning-oriented probe might be, "What, to you, is 'a period of relapse?'" while a recall probe could be, "What time period were you thinking about when answering that question?". They were also asked paraphrasing questions, process-oriented probes, evaluative probes and elaborative probes as well as general questions about missing concepts.

Since consent to record cognitive interviews was not granted by experts, extensive notes were taken during and after the interview, with some analysis done in real-time to generate live feedback. Changes were iteratively tested, and consensus was determined when few or no further modifications were proposed, resulting in the final version of CARE-12. A summary of modifications is provided in Appendix B.

Phase 2 - Psychometric Validation

Design

Phase 2 served as the primary recruitment phase, focusing on the psychometric evaluation of CARE-12. This phase aimed to assess its structural validity, internal consistency, and construct validity.

Participants completed the revised CARE-12 alongside validated measures of guilt, shame, and Expressed Emotion (EE), as well as a demographics questionnaire. The anonymous survey, developed using Qualtrics was distributed between March and June 2022.

Participants

Recruitment. Participants were informal carers who self-selected for involvement in response to invitations sent via third sector organisations (such as UK-based Beat or US-based Feast, which both provide support for those affected by eating disorders), social media (such as

Reddit), and caregiver email distribution lists. Invitations for prospective participants or group moderators included an introduction to the survey, the participant information sheet and survey link (see Ethics Proposal).

Inclusion and Exclusion Criteria. Participants were eligible if they were English readers, 18 years or older, and provided informal care to a friend or relative with long-term mental health needs. Long-term mental health needs were defined as receiving professional input for over six months. Neurological conditions and developmental disabilities were excluded unless they co-occurred with a mental health condition.

Hypotheses and Analysis Plan

It was hypothesised that CARE subscales would demonstrate adequate internal consistency (Cronbach's α = .70–.95) and structural validity. Exploratory factor analysis (EFA) with principal components analysis (PCA) was conducted to determine the factor structure. Based on previous research (Messham, 2014), guilt, shame, and blame were expected to emerge as distinct factors, while externalisation may not be retained. Guilt, blame, and externalisation were hypothesised as unidimensional, whereas shame was expected to be multidimensional.

Convergent validity was assessed by correlating CARE-12 subscales with established guilt and shame measures. Strong correlations (r > .50) were expected for CARE shame and guilt with similar constructs, while discriminant validity was examined through expected weak correlations (r < .30) between CARE guilt and other guilt measures. Predictive validity was assessed using correlations between CARE subscales and EE, expecting moderate correlations (.30–.70)

Power Calculation. A priori power analyses using G*Power (Faul et al., 2009) indicated 207 participants were required to detect a small-to-moderate effect (r = 0.25, α =

0.05, power = 0.90). The final sample of 251 exceeded this requirement and met COSMIN recommendations for EFA (5:1 participant-to-item ratio).

Materials

The self-report survey package included five anonymous questionnaires: a demographic questionnaire, the updated CARE-12, the State Shame and Guilt Scale (SSGS; Marshall, 1994), the Test of Self-Conscious Affect-3 (TOSCA-3: Tangney et al., 2000) and the Family Questionnaire (FQ: Wiedemann et al., 2002). All were available in English in both paper and electronic formats.

Demographic Questionnaire. The demographics questionnaire collected sociodemographic data, details about the care recipient, the nature of the support provided, their relationship, and the relative's mental health needs (see Table 2, 3 and 4).

CARE-12. Following revisions in Phase 1, the CARE-12 retained the original structure of the CARE-16 but assessed carers' emotional experiences using 12 hypothetical caregiving scenarios. For each scenario, the order of guilt, shame, blame, and externalisation items was randomised, but all participants received them in the same fixed order. Responses were rated on a 5-point Likert scale ranging from 1 (not likely) to 5 (very likely). Each subscale allows scores to be summed for a total subscale score. Internal consistency was good for guilt ($\alpha = 0.89$), shame ($\alpha = 0.88$), and blame ($\alpha = 0.89$), though lower for externalisation ($\alpha = 0.76$). Previous studies on CARE-16 (Messham, 2014) demonstrated good test-retest reliability across the subscales: guilt/self-blame ($r = 0.82$), shame ($r = 0.89$), blame ($r = 0.95$) and externalisation ($r = 0.76$).

SSGS. The SSGS assesses momentary experiences of shame and guilt using 10 self-report items on a 5-point Likert scale (1 = not at all to 5 = very strongly). Cronbach's alpha values in this study were good for shame (0.85) and guilt (0.89). The SSGS was chosen for its ability to measure temporary emotional states independently of situational contexts, minimising environmental or moral influences on guilt measurement. Additionally, it is a direct assessment tool that does not require respondents to understand guilt or shame, which should minimise bias and increase accuracy (Tilghman-Osborne et al., 2010).

TOSCA-3. Guilt and shame proneness were assessed using the shortened TOSCA-3, which evaluates responses to 11 guilt- and shame-inducing scenarios on 5-point Likert scales (1 = not likely to 5 = very likely). Cronbach's α values from this study were good for shame (.85) and acceptable for guilt (.74). Recent research shows satisfactory test-retest reliability for shame ($r = 0.71$) and guilt ($r = 0.77$) (Gao et al., 2013). The TOSCA-3 was chosen for its ability to distinguish between shame and guilt, its strong empirical support, and its prominence in mental health caregiver research (Cherry et al., 2017).

FQ. EE was measured using the FQ, a brief, self-report measure correlating highly with the Camberwell Family Interview (Vaughn & Leff, 1976). Participants rate 10 statements for each subscale, CC and EOI, on 4-point Likert scales (1 = never/very rarely to 4 = very often). The FQ has good internal consistency (CC: $\alpha = 0.86$; EOI: $\alpha = 0.79$) in this study. The original validation study showed good test-retest reliability (CC: $r = 0.83$; EOI: $r = 0.72$) (Wiedemann et al., 2002). The FQ was selected for its comprehensive assessment of family dynamics, strong empirical support, and widespread use in EE research and this research area (Cherry et al., 2017; Hinojosa-Marqués et al., 2019).

Phase 3 – Reliability

Design

Phase 3 assessed the stability of CARE-12 scores over time through a two-week test-retest design.

Participants and Survey Administration

Participants were a subsample from Phase 2 who agreed to participate in Phase 3 two weeks later. Participants who consented completed CARE-12 again via an automated Qualtrics email with a unique reference number to ensure confidentiality while linking responses.

Hypotheses and Analysis Plan

It was expected that Time 1 and Time 2 scores would be stable over time, with Spearman’s rho values above .70. Intra-rater reliability was anticipated to be above .40, as assessed using weighted kappa. Intra-rater measurement error, as assessed through specific percentage agreement, would meet the acceptable threshold for survey research (≥ 60%), indicating adequate response consistency over time.

Power Calculation. For Phase 3, a power analysis determined that 14 participant pairs were required to detect a moderate effect ($r = 0.70$, $\alpha = 0.05$, power = 0.90). The final sample of 31 pairs exceeded this threshold. These calculations adhered to COSMIN guidelines (Prinsen et al., 2018) for sample adequacy.

Results

Phase 1 - Content Validity and Interpretability

Four interviews with subject-matter experts and five with experiential experts were conducted to evaluate the content validity and interpretability of CARE-12. This sample size meets COSMIN (Terwee et al., 2018) standards. The issues identified and subsequent modifications are detailed in Appendix B.

Interviews with subject-matter experts focused on the relevance and clarity of CARE-12, leading to significant revisions, particularly in the operational definitions for item responses. Key adjustments included adopting Tangney's (1996) widely accepted definition of guilt, which emphasises an urge for relationship repair. Additionally, shame was refined to include internalised and externalised aspects, excluding externally sourced shame (Gilbert, 2003; Kim et al., 2011).

Hypothetical care-related scenarios were deemed relevant, comprehensive and appropriate. Scenarios incompatible with the hypothesised responses were removed or iteratively modified for neutrality and inclusivity until consensus was reached. This broadened the scale's applicability beyond psychosis-focused caregivers. Experts also provided feedback on administration, instructions and scoring.

The revised version of the CARE-12 underwent rigorous testing through cognitive interviews with individuals with lived experience, confirming face validity, relevance, comprehensibility and comprehensiveness. Modifications reduced respondent discomfort or confusion, improved readability, and clarified instructions, resulting in a user-friendly, comprehensive, and relevant scale.

Expert Characteristics

The subject-matter experts were UK-based clinical psychologists with relevant clinical and research experience: two specialised in EE, four in guilt and shame interventions (e.g., compassion-focused therapy), and three in working with caregivers.

The five experiential experts were female, three from the UK and two from Australia, aged 18–65. They had diverse backgrounds, with the characteristics of the experiential experts and their relatives further outlined in Table 2 and 3, respectively. Table 4 reports the mental health needs of the relatives. These tables also report characteristics of the participants and their relatives from Phase 2.

[Insert Table 2]

[Insert Table 3]

[Insert Table 4]

Phase 2 - Reliability and Validity

Participants

Table 2

Characteristics of Experts by Experience (Phase 1) and Characteristics of Participants (Phase 2)

Characteristic	Experts by experience		Participants	
	M	*SD*	*M*	*SD*
Age				
Years	47.4	17.67	38.6	12.8
Min-max	18-65		18-72	

Characteristic	*n*	Percentage	*n*	Percentage
Gender				
Female	5	100%	143	66%
Male	0	0%	43	20%
Third gender	0	0%	30	14%
Prefer not to say	0	0%	3	1%
Country of residence				
Asia	0	0%	2	1%
Australia	2	40%	13	6%
Canada	0	0%	18	8%
Central America	0	0%	2	1%
Europe	0	0%	10	5%
Africa	0	0%	2	1%
NZ	0	0%	5	2%
UK	3	60%	34	16%
USA	0	0%	124	57%
Unclear	0	0%	9	4%
Ethnicity				
White	4	80%	174	79%
Asian	0	0%	8	4%
Black	0	0%	4	2%
Indigenous (North America)	0	0%	2	1%
Latinx	0	0%	9	4%
Mixed	1	20%	2	1%
Prefer not to say/ unsure	0	0%	20	9%

	Experts by Experience		Participants	
Characteristic	*n*	Percentage	*n*	Percentage
Occupational status				
Full-time employed	2	40%	116	53%
Part time employed	0	0%	49	22%
Unpaid work only (caregiver, student, volunteer, etc)	2	40%	25	11%
Retired	1	20%	9	4%
Unemployed or looking for work	0	0%	20	9%
Partnership status				
Single	3	60%	36	16%
Partnered	1	20%	72	33%
Married	1	20%	98	45%
Divorced/separated	0	0%	11	5%
Widowed	0	0%	2	1%
Education				
No schooling	0	0%	1	0.5%
Some schooling but not completed high school (or equivalent)	1	20%	3	1%
High school (or equivalent)	1	20%	19	9%
Trade/vocational school	0	0%	7	3%
Some university	1	20%	51	23%
Bachelor's degree	1	20%	66	30%
Post-graduate education	1	20%	72	33%
Living with care recipient				
Yes	3	60%	140	64%
No	2	40%	81	36%
People in household				
One	1	20%	29	13%
Two	2	40%	67	31%
Three	1	20%	50	23%
Four	1	20%	51	23%

Characteristic	Experts by Experience *n*	Experts by Experience Percentage	Participants *n*	Participants Percentage
People in household, continued				
Five	0	0%	15	7%
Six	0	0%	7	3%
Number of dependents				
None	3	60%	114	52%
One	1	20%	35	16%
Two	1	20%	53	24%
Three or more	0	0%	17	8%

Note. $N = 5$ for experts by experience and $N = 219$ for participants. In accordance with style guidelines, percentages have been rounded where possible.

Table 3

Characteristics of Relatives and Care Recipients of Experts by Experience (Phase 1) and Participants (Phase 2)

Characteristic	Expert's relative		Participant's relative	
	M	*SD*	*M*	*SD*
Age				
Years	35.8	10.62	31.3	13.2
(min-max)	(18-45)		(11-80)	

Characteristic	*n*	Percent-age	*n*	Percent-age
Gender				
Female	5	100%	118	54%
Male			80	36%
Third gender			16	7%
Prefer not to say			5	2%
Currently receiving professional support?				
Yes	5	100%	173	79%
No			46	20%
Participant's relationship to care-recipient				
Mother	2	40%	59	27%
Father			5	2%
Step mother			1	0.5%
Spouse/partner			109	49%
Adult child	1	20%	14	6%
Extended relative (including sibling)	1	20%	10	5%
Friend	1	20%	21	9%
Living with care recipient?				
Living together	3	60%	139	63%
Not living together	2	40%	80	36%

Characteristic	Expert's relative		Participant's relative	
	n	Percent-age	*n*	Percent-age
Active contact with care-recipient (hours per week)				
Less than10	1	20%	54	25%
11-20	1	20%	28	13%
21-50	3	60%	66	31%
51-100			57	26%
More than 100			14	7%
Type of support provided				
Financial	3	60%	135	61%
Emotional	5	100%	220	100%
Practical	5	100%	154	70%
Employment status				
Working	2	40%	126	57%
Studying or volunteering	1	20%	56	25%
Caring for dependents	1	20%	27	12%
Not working and no dependents	1	20%	61	28%
Education				
Completed high school	1	20%		
Some university	3	60%		
Bachelor's degree	1	20%		
Number of dependents				
None	2	40%		
One	3	60%		

Note. $N = 5$ for experts' relatives and $N = 219$ for participants' relative. In accordance with style guidelines, percentages have been rounded where possible.

Table 4

Mental Health Needs of Relatives and Care Recipients of Experts by Experience (Phase 1) and Participants (Phase 2)

	Expert's relative		Participant's relative	
Mental Health Need	*n*	Percentage	*n*	Percentage
Anxiety	2	40%	152	69%
Depression	2	40%	136	62%
Post traumatic Stress			85	39%
Stress			79	36%
Eating difficulties			76	35%
Bipolar	1	20%	68	31%
Attention and hyperactivity			58	26%
Personality/relationship trauma			49	22%
Obsessions and compulsions			38	17%
Addiction			35	16%
Psychosis	1	20%	13	6%
Dissociative identity			13	6%
Complex post-traumatic stress			12	5%
Other [a]			5	8%
Autism spectrum			5	2%
Undiagnosed			4	2%
Opposition and defiance			3	1%
Total	6	120%	839	380%

Note. N = 5 for experts' relatives and *N* = 219 for participants' relative. Experts by experience and participants reported this information, and could report more than one need.

[a] Other mental health needs reported by the participant included bereavement (n = 1), dysphoria (*n* = 1), gender dysphoria (*n* = 1), paranoia (*n* = 1), suicidality (*n* = 1).

Of the 386 participants who initiated the survey, 220 fully completed it. While 135 completed only the SSGS and were excluded, 251 completed the CARE-12, exceeding COSMIN (Prinsen et al., 2018) standards for sample size. Among these, 31 did not complete the FQ, TOSCA-3, and demographics survey; however, 220 responses met the power requirements for correlational analyses. Partial responses were retained for analysis when feasible. Table 2 includes participant characteristics, and Table 3 includes the characteristics of their relatives. Table 4 reports the mental health needs of relatives.

Data Preparation

Participants missing CARE-12 data were excluded from analysis. Missing Value Analysis indicated most missing data were negligible (<5%; Jakobsen et al., 2017). For TOSCA-3 items with >5% missing data, imputation was considered but not used due to standard error risk (Jakobsen et al., 2017). As a result, the number of cases for TOSCA-3 vary in comparison to other analyses.

Descriptive Statistics

Descriptive statistics of study variables reported in Table 5 indicate only guilt proneness differed significantly, with women scoring higher. However, living together significantly increased caregiving-related shame, EOI, and CC. Other relationship dynamics were not analysed due to limited numbers, which could increase the likelihood of Type II errors.

Based on Wiedemann et al. (2002) cut-offs, 199 out of 239 participants (83%) had high EE, based on scores above 23 for EOI or above 27 for CC. Further group analyses are provided in Appendix C. As reported in Table 5, high EE groups had significantly higher levels of guilt and shame across all measures, except shame proneness was not significantly different between the EOI groups.

[Insert Table 5]

Table 5

Descriptive Statistics for all Variables in the Whole Sample and Across Relevant Groups

		CARE 11 guilt	CARE-11 shame	EOI	CC	Active guilt	Active shame	Guilt proneness	Shame proneness
Female	*N*	144	144	144	144	144	144	139	123
	M	35.3	29.5	31.1	24.3	11.1	11.3	47.6*	36.6
	SD	10.7	11.5	5.4	6.5	5.1	5.2	5.2	9.5
Male	*N*	43	43	43	43	43	43	40	38
	M	35.6	30.2	30.7	25.0	12.3	13.0	43.8	33.7
	SD	8.9	9.8	5.3	7.4	5.9	6.4	7.0	10.1
Living together	*N*	140	140	140	140	140	140	134	122
	M	35.7	30.9*	31.5**	25.4**	11.5	12.0	46.5	36.3
	SD	10.5	11.4	5.4	6.9	5.4	5.6	6.3	10.0
Not living together	*N*	81	81	81	81	81	81	79	71
	M	34.4	27.7	29.3	22.5	11.4	11.7	46.5	37.2
	SD	9.6	10.6	5.5	6.2	5.7	5.5	5.8	9.1

		CARE 11 guilt	CARE-11 shame	EOI	CC	Active guilt	Active shame	Guilt proneness	Shame proneness
Mother	*N*	59	59	59	59	59	59	57	54
	M	36.8	30.9	31.5	24.2	11.0	10.6	47.0*	36.2
	SD	10.2	11.3	4.7	6.1	5.2	5.1	5.4	9.9
Father	*N*	5	5	5	5	5	5	5	5
	M	36.4	32.2	27.2	23.6	11.0	13.6	40.4	34.2
	SD	14.0	13.4	8.3	7.1	6.0	3.0	14.9	7.5
Spouse or partner	*N*	109	109	109	109	109	109	107	94
	M	35.3	30.0	30.7	25.4	11.4	12.1	46.5	36.4
	SD	9.8	10.4	5.8	7.4	5.5	5.6	6.0	9.3
Adult child	*N*	14	14	14	14	14	14	13	12
	M	30.6	25.5	30.8	24.0	10.3	10.8	47.0	32.5
	SD	13.0	13.2	6.1	5.6	4.1	4.2	5.4	10.2
Other relative or friend	*N*	31	31	31	31	31	31	29	28
	M	35.0	28.7	29.7	21.9	13.2	14.0	46.2	40.9*
	SD	9.0	11.7	5.2	6.0	6.4	6.3	5.9	9.1

		CARE 11 guilt	CARE-11 shame	EOI	CC	Active guilt	Active shame	Guilt proneness	Shame proneness
High EOI	*N*	183	183	183	183	183	183	168	150
	M	36.7***	31.4***	33.0***	25.6***	12.3**	13.1***	47.2**	37.5
	SD	9.8	10.8	3.6	6.4	5.7	5.7	5.3	9.4
Low EOI	*N*	56	56	56	56	56	56	51	49
	M	30.7	23.8	22.4	19.6	9.6	9.0	44.3	34.8
	SD	9.5	9.5	3.4	6.0	4.9	4.2	7.8	10.1
High CC	*N*	134	134	134	134	134	134	120	111
	M	36.4	32.6***	32.8***	29.2***	12.7**	13.6***	47.3*	38.3*
	SD	9.9	10.6	4.5	4.3	5.8	6.0	5.6	8.9
Low CC	*N*	105	105	105	105	105	105	99	88
	M	33.9	25.8	27.6	17.9	10.4	10.3	45.6	35.1
	SD	10.0	10.2	5.8	3.2	5.0	4.5	6.6	10.3
Total sample	*N*	251	251	239	239	251	251	219	199
	M	35.2	29.5	30.5	24.2	11.6	12.1	46.5	36.8
	SD	10.0	10.9	5.7	6.8	5.6	5.6	6.1	9.6

Note. For all measures, lower scores indicate lower levels of the measured variable.

* $p < .05$

** $p < .01$

*** $p < .001$

Data Analysis

Assumption Testing. Data normality and linearity were assessed using Shapiro-Wilk's test ($p < 0.05$), histograms, and P-Plots. SSGS variables were not normally distributed however, the large sample size allowed for parametric calculations under central limit theorem (Kwak & Kim, 2017). Given the ordinal nature of the data, Spearman’s rho was employed for univariate analyses and interpreted according to Dancey and Reidy (2020).

Construct Validity

Structural Validity. To assess the adequacy of CARE-12 in reflecting the emotional experience of caregivers, a Principal Components Analysis (PCA) was conducted. Before analysis, data were assessed for normality and linearity. Although normality was confirmed, linearity was initially lacking, with the determinant of the correlation matrix below the acceptable threshold. Low-correlation items are typically removed to correct this, however, maintaining the CARE survey's layout was crucial to preserving interpretability and content validity, as assessed in Phase 1. Therefore, extraction removed entire variables or scenarios, not single items. Low-correlation items were sequentially removed: first the externalisation variable, then the blame variable, and finally Scenario 4, achieving an acceptable determinant.

With linearity established, PCA proceeded. Bartlett's test of sphericity confirmed factorability ($p < 0.001$). The sample size was adequate as the Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy was very high (0.933), supporting factor analysis.

Four components with values greater than 1 explained 42.3%, 6.9%, 5.6%, and 4.7% of the variance, respectively, accounting for 59.5% of the total variance. The data met Kaiser’s criterion for retaining factors with eigenvalues greater than 1, although Factor 3 was considered unreliable due to a small number of factor loadings with communalities above 0.6 (Guadagnoli & Velicer, 1988). This lead guilt items for scenario 7a and 12a to be loaded onto Factor 1. The rotated solution revealed a simple structure (Thurstone, 1947), with Factors 1, 2, and 4 exhibiting interrelationships in the structure matrix, justifying oblique rotation. The remaining factors aligned with the emotional responses intended with component loadings and communalities of the oblique rotated solution presented in the pattern matrix in Table 6. For comprehensiveness, the structure matrix is presented in Table 7. Component 1 emphasised guilt, Component 2 internalised shame, and Component 4 externalised shame. The distribution of shame items over two factors reflected the multidimensional nature of shame (Gilbert, 2003; Kim et al., 2011). The guilt items 7 and 12, which formed Component 3, represented instances where the caregiver took responsibility for the situation and expressed clear intentions to repair or change future behaviour.

Most items strongly aligned with their expected factors. Items not precisely loading still showed strong loadings with the original factor and were assigned based on their operant definition, following Field's (2018) guidance to consider face validity. Although shame item 3 lacked an avoidance urge, it was confirmed as a shame item. Guilt items 1 and 11 reflect caregivers' perception of responsibility due to failing to meet personal standards, with this failure aspect linked to shame (Tangney & Tracy, 2012).

The final model was an adequate fit as only 33% of the residuals were non-redundant with a value greater than .05. Overall, the PCA showed that the CARE scale was a valid measure of guilt and shame, with a clear and interpretable factor structure. The resulting final component structure (see Table 8) served as the basis for all subsequent analyses in this paper and is referred to as CARE-11.

[Insert Table 6]

[Insert Table 7]

[Insert Table 8]

Table 6

Pattern Matrix with Factor Loadings of PCA with Oblique Rotation for CARE-12

	Factor loading			
CARE items	1	2	3	4
8. Guilt - I would think about what I should do differently in order to prevent my relative's distress.	0.74			
6. Guilt - I would wonder if there was something I missed or did wrong and try and make up for it.	0.73			
2. Guilt - I would feel bad about the times I might have helped more but didn't and think about ways I could make up for this.	0.69			
5. Guilt - I would feel bad about my role in this and think about what I could do to help them.	0.68			
6. Internalised Shame - I would feel as if I have failed.	0.65			
10. Guilt - I would feel bad about this and would like to do something to make them feel better about it.	0.65			
3. Guilt - I would feel bad that I prioritised other commitments and would try to make amends.	0.65			
9. Guilt - I would think about where I went wrong and show I am sorry that I upset them.	0.58			
2. Internalised Shame - I would feel like I'm a failure.	0.55			
3. Internalised Shame - I would think I am selfish for leaving them.	0.51			
8. Internalised Shame - I would feel small and avoid the topic.		0.79		
10. Internalised Shame - I would feel not good enough so avoid thinking about it.		0.69		
7. Internalised Shame - I would feel like I'm not good enough and want to end the conversation.		0.67		
9. Externalised Shame - I would think other families seem to manage without having these problems, why can't we?		0.55		
12. Internalised Shame - I would feel small for not being able to care for my relative without help.		0.52		
12. Guilt - I would feel bad for not asking for their permission and think about how we can repair this.			0.68	

CARE Items	Factor loading 1	 2	 3	 4
7. Guilt - I would think about how they might be right, I could have done things differently and will try and change how I do things in future.			0.48	
5. Externalised Shame - I would feel like all eyes are on me.				0.79
1. Externalised Shame - I would worry people think I am not a good carer.				0.76
11. Externalised Shame - I would think about how other people will judge me because of this.				0.6
1. Guilt - I would worry if this was down to me and the times I may not have supported them as well as I would like.				0.43
11. Guilt - I would think about the times where I could have supported their independence but didn’t and plan how to change this.				0.41

Note. N = 251. The extraction method was principal components analysis with an oblique (Oblimin with Kaiser Normalisation) rotation with factor loadings above .30. Rotation converged in 14 iterations. Factor 1 = guilt, concern about the consequences of mistakes and a desire to compensate; 2 = internalised shame, feeling inadequate and wanting to hide; Factor 3 = actively taking responsibility and planning repair; Factor 4 = externalised shame, feeling preoccupied with how the self is perceived by others.

Table 7

Structure Matrix with Factor Loadings of PCA with Oblique Rotation for CARE-12

CARE Item	Factor loading			
	1	2	3	4
5. Guilt - I would feel bad about my role in this and think about what I could do to help them.	0.80	0.48		0.44
6. Internalised Shame - I would feel as if I have failed.	0.76	0.50		0.59
3. Guilt - I would feel bad that I prioritised other commitments and would try to make amends.	0.74	0.40		
3. Shame Internalised - I would think I am selfish for leaving them.	0.72	0.54		0.48
9. Guilt - I would think about where I went wrong and show I am sorry that I upset them.	0.72	0.49		
2. Guilt - I would feel bad about the times I might have helped more but didn't and think about ways I could make up for this.	0.71	0.44		
8. Guilt - I would think about what I should do differently in order to prevent my relative's distress.	0.70			
10. Guilt - I would feel bad about this and would like to do something to make them feel better about it.	0.70			
6. Guilt - I would wonder if there was something I missed or did wrong and try and make up for it.	0.69			0.42
2. Internalised Shame - I would feel like I'm a failure.	0.68	0.52		0.59
8. Internalised Shame - I would feel small and avoid the topic.		0.81		
10. Internalised Shame - I would feel not good enough so avoid thinking about it.	0.56	0.75		
7. Internalised Shame - I would feel like I'm not good enough and want to end the conversation.	0.43	0.74		
12. Internalised Shame - I would feel small for not being able to care for my relative without help.	0.46	0.66		0.44

CARE item	Factor loading			
	1	2	3	4
9. Externalised Shame - I would think other families seem to manage without having these problems, why can’t we?		0.60		0.47
12. Guilt - I would feel bad for not asking for their permission and think about how we can repair this.			0.70	
7. Guilt - I would think about how they might be right, I could have done things differently and will try and change how I do things in future.	0.58		0.59	0.42
5. Externalised Shame - I would feel like all eyes are on me.				0.80
1. Externalised Shame - I would worry people think I am not a good carer.	0.45			0.78
11. Externalised Shame - I would think about how other people will judge me because of this.		0.55		0.70
1. Guilt - I would worry if this was down to me and the times I may not have supported them as well as I would like.	0.55			0.58
11. Guilt - I would think about the times where I could have supported their independence but didn’t and plan how to change this.	0.56		0.44	0.57

Note. N = 251. The extraction method was principal components analysis with an oblique (Oblimin with Kaiser Normalisation) rotation with factor loadings above .30. Factor 1 = guilt, concern about the consequences of mistakes and a desire to compensate; 2 = internalised shame, feeling inadequate and wanting to hide; Factor 3 = actively taking responsibility and planning repair; Factor 4 = externalised shame, feeling preoccupied with how the self is perceived by others.

Table 8

Structure Matrix with the Factor Loadings of the CARE-11

	Factor loading			
	1	2	3	4
4. Guilt - I would feel bad about my role in this and think about what I could do to help them.	**0.80**	0.48		0.44
3. Guilt - I would feel bad that I prioritised other commitments and would try to make amends.	**0.74**	0.40		
8. Guilt - I would think about where I went wrong and show I am sorry that I upset them.	**0.72**	0.49		
2. Guilt - I would feel bad about the times I might have helped more but didn't and think about ways I could make up for this.	**0.71**	0.44		
7. Guilt - I would think about what I should do differently in order to prevent my relative's distress.	**0.70**			
9. Guilt - I would feel bad about this and would like to do something to make them feel better about it.	**0.70**			
5. Guilt - I would wonder if there was something I missed or did wrong and try and make up for it.	**0.69**			0.42
1. Guilt - I would worry if this was down to me and the times I may not have supported them as well as I would like.	**0.55**			0.58
10. Guilt - I would think about the times where I could have supported their independence, but didn't, and plan how to change this.	**0.56**		0.44	0.57
6. Guilt - I would think about how they might be right, I could have done things differently and will try and change how I do things in future.	**0.58**		0.59	0.42
11. Guilt - I would feel bad for not asking for their permission and think about how we can repair this.			0.70	

7. Internalised Shame - I would feel small and avoid the topic.		**0.81**	
9. Internalised Shame - I would feel not good enough so avoid thinking about it.	0.56	**0.75**	
6. Internalised Shame - I would feel like I'm not good enough and want to end the conversation.	0.43	**0.74**	
11. Internalised Shame - I would feel small for not being able to care for my relative without help.	0.46	**0.66**	0.44
3. Internalised Shame - I would think I am selfish for leaving them.	0.72	**0.54**	0.48
4. Shame Externalised - I would feel like all eyes are on me.			**0.80**
1. Shame Externalised - I would worry people think I am not a good carer.	0.45		**0.78**
10. Shame Externalised - I would think about how other people will judge me because of this.		0.55	**0.70**
2. Externalised Shame - I would feel like I'm a failure.	0.68	0.52	**0.59**
5. Externalised Shame - I would feel as if I have failed.	0.76	0.50	**0.59**
8. Externalised Shame - I would think other families seem to manage without having these problems, why can't we?		0.60	**0.47**

Note. *N* = 251. The extraction method was principal components analysis with an oblique (Oblimin with Kaiser Normalisation) rotation with factor loadings above .30. Where an item loads onto more than one factor, the loading to which the item is allocated is in bold. Factor 1 = guilt, concern about the consequences of mistakes and a desire to compensate; 2 =

Note (continued)

internalised shame, feeling inadequate and wanting to hide. Factor 3 = actively taking responsibility and planning repair; Factor 4 = externalised shame, feeling preoccupied with how the self is perceived by others.

Unidimensionality. The PCA showed the guilt subscale was unidimensional, explaining 51% of variance. The shame subscale was multifaceted, explaining 58% of variance across the two components, internalised and externalised shame (see Table 9).

[Insert Table 9]

Hypothesis Testing for Construct Validity

Convergent and Divergent Validity Properties. Results presented in Table 10 demonstrate caregiving-related shame showed a strong correlation with shame proneness and state shame. Meanwhile, caregiving-related guilt had moderate correlations with guilt proneness and a strong correlation with state guilt. A Fisher's Z test indicates that the association was not significantly different ($z = 1.25$, $p = 0.212$).

[Insert Table 10]

Predictive Validity Properties. The relationship between CARE-11 and FQ was quantified through correlational analyses with Fisher's z-test indicating if the differences were statistically significant. Results presented in Table 10 show that EOI has a strong positive relationship to guilt and shame. A Fisher's Z test indicates that the association was not significantly different ($z = -0.89$, $p = 0.372$). CC showed similar moderate positive correlations with shame, and a significant but negligible relation to guilt. A Fisher's Z test indicates that the association with shame was significantly larger than with guilt ($z = -2.45$, $p = 0.014$).

Reliability

Internal Consistency. The internal consistency of the CARE subscales was evidenced by Cronbach's alphas, categorised as good for guilt ($\alpha = 0.89$), shame ($\alpha = 0.88$) (see Appendix C for blame and externalisation) (George & Mallery, 2020). Cronbach's alpha assumes unidimensionality, so Cronbach's alpha for both internalised shame ($\alpha = 0.87$) and externalised shame ($\alpha = 0.75$) are reported. Removing individual items did not improve alphas

Table 9

Unidimensionality Results from a PCA of the CARE-11 Shame Subscales

	Factor	
Shame Items	1	2
4. Externalised Shame - I would feel like all eyes are on me.	0.774	
1. Externalised Shame - I would worry people think I am not a good carer.	0.728	
10. Externalised Shame - I would think about how other people will judge me because of this.	0.699	
2. Externalised Shame - I would feel like I'm a failure.	**0.617**	0.458
5. Externalised Shame - I would feel as if I have failed.	**0.599**	0.488
8. Externalised Shame - I would think other families seem to manage without having these problems, why can't we?	0.492	
9. Internalised Shame - I would feel not good enough so avoid thinking about it.		0.804
6. Internalised Shame - I would feel like I'm not good enough and want to end the conversation.		0.782
7. Internalised Shame - I would feel small and avoid the topic.		0.763
3. Internalised Shame - I would think I am selfish for leaving them.	0.395	**0.654**

Note. N = 251. The extraction method principal components analysis with an orthogonal (Varimax with Kaiser Normalisation) rotation with factor loadings above .30. Rotation converged in three iterations. Where an item loads onto more than one factor, the loading to which the item is allocated is in bold. Factor 1 = externalised shame, feeling preoccupied with how the self is perceived by others; Factor 2 = internalised shame, feeling inadequate and wanting to hide. Factor 3 = actively taking responsibility and planning repair; Factor 4 =

Note (continued)

externalised shame, feeling preoccupied with how the self is perceived by others. The shame Item 9 was loaded onto Factor 4 (externalised shame) due to its placement when guilt items were not included in the PCA (see Table 11). Following the removal of Items 4, the item numbering in the CARE-11 differs from earlier tables but aligns with the final version presented in Appendix D.

Table 10

Spearman's Rho Correlations of CARE-11 with Measures of EE, State Guilt and Shame, and Proneness to Guilt and Shame.

					CARE-11 Subscale	
Measure	Subscale	*n*	*M*	*SD*	Guilt	Shame
Caregiving emotions (CARE-11)	Guilt	251	35.2	10.0	-	.78**
	Shame	251	29.5	10.9	.78**	-
EE (FQ)	EOI	239	30.5	5.7	0.40**	.46**
	CC	239	24.2	6.8	0.14*	.35**
State emotions (SSGS)	Guilt	251	11.6	5.6	0.42**	.48**
	Shame	251	12.1	5.6	0.41**	.49**
Proneness to emotions (TOSCA-3)	Guilt	219	46.5	6.1	0.32**	.25**
	Shame	199	36.8	9.6	0.51**	.55**

Note. For all measures, lower scores indicate lower levels of the measured variable.

* $p < .05$

** $p < .001$

and all were within the acceptable range of 0.70 to 0.95, indicating no redundant items (Tavakol & Dennick, 2011; Terwee et al., 2007).

Test-Retest Reliability. To assess test-retest reliability, Time 1 scores were compared with Time 2 scores, measured at least two weeks apart. The results, in Table 11, revealed very strong correlations, indicating an acceptable level of reproducibility. High Spearman's rho values suggest the instrument consistently identifies high and low scorers, supporting its stability for repeated measurements.

[Insert Table 11]

Intra-Rater Reliability. To assess partial chance agreement weighted kappa (Kw) with linear weights was calculated to determine the agreement between specific Time 1 and Time 2 scores (Cicchetti & Allison, 1971). The weighted kappa coefficients for all items within the subscales (Table 12) suggest moderate disagreement between the Time 1 and Time 2 scores (Landis & Koch, 1977).

[Insert Table 12]

Intra-Rater Measurement Error. To evaluate measurement error in ordinal data and explore kappa score heterogeneity in clinical measures, the proportion of specific agreement between Time 1 and Time 2 scores were calculated (De Vet et al., 2006). They were interpreted using Landis and Koch's (1977) categories (see Table 13 and 14). On the guilt subscale, "very likely" and "not likely" categories showed substantial and moderate agreement, respectively. Middle Likert categories (2, 3 & 4) generally showed fair or slight agreement, indicating variability over time. For shame, "not likely" showed moderate agreement, while the others showed only slight agreement. This suggests higher measurement error and less consistency in shame ratings. On both subscales, Scenario 1 had very poor agreement.

[Insert Table 13]

[Insert Table 14]

Table 11

Spearman's Rho Correlation Coefficient at Time 1 and Time 2 for CARE-11 Subscales

	Time 1			
	Guilt	Shame	Internalised Shame	Externalised Shame
Time 2				
Guilt	.82***	-	-	-
Total Shame	-	.83***	-	-
Internalised Shame	-	-	.75***	-
Externalised Shame	-	-	-	.83***

Note. N = 51.

*** *p* < .001

Table 12

Weighted Kappa Coefficient for All Items Within CARE-11 with Landis & Koch (1977) Classification

Subscale/Dimension	Kappa	*P* value	95% CI	Classification
Guilt	.579	$p < .001$	[.476, .681]	Moderate
Shame Total	.590	$p < .001$	[.490, .690]	Moderate
Internalised Shame	.521	$p < .001$	[.399, .643]	Moderate
Externalised Shame	.618	$p < .001$	[.515, .721]	Substantial

Note. $N = 55$.

Table 13

Specific Percentage Agreement for the Guilt Subscale

	Likert Rating				
Guilt item	Not likely	2	3	4	Very likely
Scenario 1	31%	50%	0%	30%	22%
Scenario 2	29%	30%	20%	30%	62%
Scenario 3	50%	48%	15%	14%	56%
Scenario 4	44%	39%	77%	62%	74%
Scenario 5	55%	67%	55%	59%	63%
Scenario 6	0%	27%	29%	24%	55%
Scenario 7	50%	30%	19%	15%	50%
Scenario 8	35%	35%	20%	13%	42%
Scenario 9	35%	35%	20%	13%	42%
Scenario 10	53%	12%	25%	19%	50%
Scenario 11	41%	9%	8%	30%	35%
Scenario 12	36%	35%	12%	31%	65%

Note. N = 55.

Table 14

Specific Percentage Agreement for the Shame Subscale with Shame Dimension Identified

		Likert Rating				
Shame item	Shame Dimension	Not likely	2	3	4	Very likely
Scenario 1	Externalised	38%	11%	24%	11%	16%
Scenario 2	Externalised	16%	18%	29%	16%	20%
Scenario 3	Internalised	31%	22%	13%	15%	20%
Scenario 4	Externalised	42%	16%	16%	13%	13%
Scenario 5	Externalised	56%	9%	16%	9%	9%
Scenario 6	Internalised	49%	10%	20%	10%	12%
Scenario 7	Internalised	49%	10%	20%	10%	12%
Scenario 8	Externalised	47%	28%	14%	4%	8%
Scenario 9	Internalised	41%	12%	18%	10%	20%
Scenario 10	Internalised	35%	12%	12%	20%	22%
Scenario 11	Externalised	53%	16%	4%	18%	10%
Scenario 12	Internalised	35%	14%	16%	20%	16%

Note. N = 55.

Discussion

This study makes a significant contribution by validating the CARE-11, a targeted measure for assessing shame and guilt in caregivers of individuals with enduring mental health needs. Adhering to COSMIN guidelines (Prinsen et al., 2018), this study confirmed measurement properties such as content and structural validity, reliability, construct validity and unidimensionality.

Content validity was prioritised with the scale refined through expert and caregiver interview feedback, enhancing its relevance and comprehensiveness. These revisions also ensured alignment with established theoretical constructs, defining guilt as an adaptive response to specific transgressions and shame as a multidimensional emotion, incorporating both internalised and externalised aspects (Tangney & Dearing, 2002; Gilbert, 2003).

Structural validity was established through a PCA, which revealed three distinct dimensions: guilt, internalised shame, and externalised shame. Guilt demonstrated good unidimensionality while the two shame dimensions reflected shame's multidimensionality. The removal of the externalisation and blame subscales streamlined the instrument; however, the exclusion of blame warrants further consideration as it is a known predictor of CC (Rothwell, 2023). The final two-factor structure of guilt and shame demonstrated acceptable internal consistency, reproducibility, convergent validity, and predictive validity properties with EE. However, the high inter-rater measurement error indicates better-defined Likert scale categories will enhance measurement stability.

Overall, the CARE-11 is validated as a reliable and insightful tool, capturing the specific emotional dynamics of caregiving. This positions it to significantly advance research and inform intervention strategies for emotional challenges in caregiving. The strengths and limitations of this approach will be discussed, highlighting the CARE-11's potential for future research and clinical applications.

Content Validity

This study prioritised content validity, the most critical measurement property according to COSMIN (Mokkink et al., 2018), through interviews with subject-matter experts and cognitive interviews with experiential experts. Revisions aligned with relevant theoretical constructs and are supported by structural validity assessments.

The overall structure and hypothetical scenarios were deemed appropriate and relevant. Cognitive interviews with carers informed the scale's comprehensibility, relevance, and comprehensiveness across diverse caregiver populations. However, cognitive interviews lacked representation from carers for romantic partners and were predominantly white, educated females. While typical of studies in this field (Cherry et al., 2017), this may limit insights into cultural variations in guilt and shame (Tilghman-Osborne et al., 2010).

Structural Validity

This study demonstrated the CARE-11 has strong structural validity by effectively capturing and differentiating between the underlying dimensions of shame and guilt in caregiving with a clear interpretable structure. According to COSMIN (Mokkink et al., 2010a), the internal structure is the second most important type of validity for an instrument. The total variance explained by CARE-11 is acceptable (Field, 2018) and typical of scenario-based measures (Tangney, 1996; Watson et al., 2016). To satisfy the linearity assumptions of PCA, the externalisation and blame subscales, along with scenario four, were removed. The exploratory PCA then identified three distinct areas of measurement: guilt, internalised shame, and externalised shame.

The CARE-11's ability to differentiate between shame and guilt aligns with theoretical frameworks that view these as related yet distinct emotions (Tangney & Dearing, 2002). This distinction addresses conflation issues identified in the original version (Messham, 2014) and enhances precision in assessing both emotions. By distinguishing shame and guilt, the CARE-

11 offers unique insights into how these emotions interact and function in relation to EE. Their very strong relationship reflects their frequent co-occurrence in situations involving culpability for harm to others (Tangney & Dearing, 2002).

The PCA reflected the multidimensional properties of shame, effectively distinguishing internalised and externalised shame. Expert feedback from Phase 1 informed the inclusion of externalised shame, aiming to offer a more comprehensive assessment of carers' internal experiences of shame. This approach aligns the CARE-11 with established theoretical frameworks (Gilbert, 2016) and provides more precise clinical insights.

Another outcome of the PCA was the exclusion of the externalisation and blame subscales to meet linearity assumptions. Externalisation was removed due to a minimal contribution to the overall scale and weak relationships to other variables (see Appendix C) and in previous validity assessments (Messham, 2014). This exclusion has streamlined the CARE-11 to be more targeted and efficient to complete. However, the removal of the blame subscale raises important considerations.

Blame, a defensive projection linked to shame, is central to high EE households (Barrowclough & Hooley, 2003; Brown, 2004; Tracy & Robins, 2006b). Rothwell (2023) identified blame as the only significant predictor of CC. Despite its relevance, blame may not have conformed to the linear structure of other self-conscious emotions in the PCA, as it is primarily an attribution rather than a distinct emotional state (Barrowclough et al., 1996). While the omission of blame has increased the focus on self-conscious emotions, enhancing content validity, this may critically undermine the measure’s utility in predicting overall EE, as blame had a larger association with EE than guilt or shame (See Appendix C). Subsequently, future studies should address the unresolved role of blame through Confirmatory Factor Analysis (CFA) methods that accommodate non-linearity.

Reliability

Internal Consistency, Reproducibility, Intra-Rater Reliability and Measurement Error

Internal consistency is crucial for assessing an instrument's internal structure and is highly valued by COSMIN standards (Mokkink et al., 2010a). This study surpassed COSMIN's (Mokkink et al., 2010b) acceptable levels, with excellent Cronbach's alpha values for guilt, indicating reliable measurement of shame and guilt among caregivers. This aligns with previous studies using CARE (Messham, 2014; Rothwell, 2023). The lower scores for internalised and externalised shame likely reflect the insufficient length of the subscales, as they were split into two for the assessment (Tavakol & Dennick, 2011).

Test-retest reliability, as measured by high Spearman's rho values, indicates that CARE-11 is reproducible over time, consistently distinguishing between high and low levels of guilt and shame. Recognising that Cronbach's alpha assumes unidimensionality and that ordinal scores might align by chance; weighted kappa scores were applied as a secondary measure. According to Landis and Koch (1977), the moderate scores observed are acceptable for survey research.

The percentage specific agreement analysis highlighted significant discrepancies in the intermediate categories for guilt and shame, particularly within the "very likely" category for shame. These discrepancies likely arise from the subjective nature of the scale's descriptions, which are only well-defined at the extremes ("not likely" and "very likely"). To enhance agreement, clear definitions for the intermediate Likert scale categories are essential. However, as we assumed stability during the test-retest period (Mokkink et al., 2023) it remains unclear whether the discrepancies arise from actual fluctuations in CARE responses or from instability in participants' emotional states. Poor agreement was most pronounced in the shame subscale and in scenarios involving complex emotional responses. This suggests that the variability may stem from the inherent challenges in assessing intense emotional experiences like shame (Kim et al., 2011). While such variability is considered acceptable within a research context (de Vet et al., 2006), future research should incorporate stability assessments as a possible confounding variable that can assist interpretation of reliability findings.

Despite some challenges, the rigorous methodology employed supports the CARE-11's suitability for research and its effectiveness in distinguishing between varying levels of guilt and shame (de Vet et al., 2006).

Hypothesis Testing for Construct Validity

Convergent and Discriminant Validity Properties

In the absence of a gold standard for measuring caregiver guilt and shame, this study used a hypothesis-driven approach to validate CARE-11, based on Tangney and Dearing’s (2003) widely accepted definitions. Utilising Dancey and Reid’s (2020) guidelines to interpret correlation strengths, caregiving shame showed strong correlations with shame-proneness and state-shame. This supports the convergent validity of the CARE-11 by highlighting the stable and pervasive nature of shame. Additionally, the absence of very strong correlations suggests that CARE-shame measures unique aspects specific to the caregiving context.

The hypothesis proposed that caregiving guilt would exhibit weak correlations with general measures of guilt-proneness and state-guilt, given its specific caregiving context. However, the findings revealed moderate to strong correlations, indicating that caregiving guilt aligns more closely with these broader forms of guilt than initially expected. This finding supports convergent validity, which should be prioritised over discriminant validity (Abma et al., 2016). Nonetheless, the unexpected outcome may result from limitations in the measures used or flawed assumptions underlying the hypothesis (Abma et al., 2016). Although the CARE and SSGS lack peer-reviewed validation studies, in hindsight stronger associations could have been reasonably expected, as different measures of guilt likely share common underlying principles. Future hypotheses should reflect this consideration.

Overall, the CARE-11 effectively captures self-conscious emotions specific to caregiving, differentiating them from generalised traits. This distinction enables research to encompass the unique emotional experiences of caregivers, which have not been previously captured due to the prevalent use of dispositional measures such as the TOSCA (Cherry et al., 2017).

Predictive Validity Properties

The hypotheses that shame would show moderate correlations with EOI and CC, and guilt would show moderate correlations with EOI but weak correlations with CC, were supported. While these fall short of the predictive validity level outlined in the COSMIN guidelines (Mokkink et al., 2017), this outcome was expected and should be contextualised (Cohen, 1988; Thompson, 2007). Within the broader context of EE, numerous factors beyond self-conscious emotions contribute to EE (Barrowclough & Hooley, 2003). As related but distinct constructs, the univariate analyses meet the anticipated thresholds for construct validity as outlined by COSMIN (Prinsen et al., 2018). Furthermore, these analyses, interpreted using classifications from Dancey and Reidy (2020), are consistent with the current literature.

The moderate positive correlations supported the hypothesised association between EOI with guilt and shame. This is consistent with previous studies showing moderate to strong associations with care-specific guilt and care-specific shame (Messham, 2014; Keith, 2011). Rothwell (2023) found for caregivers of someone with eating difficulties that guilt was a significant predictor of EOI, after controlling for other factors.

The hypothesis that shame would have a moderate positive association with CC, while guilt would be very weak or negligible, was supported. These patterns generally align with previous research; Messham found CC had a strong association with shame and a weak association with guilt, while Rothwell reported a weak association for shame and very weak association for guilt. The lower effect sizes in this study compared to Messham may be due to several factors.

First, this study and Rothwell used Spearman's rho for analyses, which is generally considered more robust for ordinal data and less susceptible to outliers (Field, 2018), compared to Pearson's correlation used by Messham. Second, the operational definition of guilt used in this study was free from self-blame. This could account for the difference if self-blame is more closely related to EE, a prospect for future research. Finally, differences in participant demographics might also play a role as Messham's participants were mostly mothers, who typically experience higher levels of EE (Fahrer et al., 2022; Hale et al., 2016).

Messham, Keith, and Rothwell are the only studies directly comparable. They used the self-report FQ to measure EE and analysed care-specific guilt and shame measures. Other studies (Bentsen et al., 1998; Brookfield, 2008; McMurrich, 2008; Peterson & Docherty, 2004; Wasserman et al., 2012; Weisman de Mamani, 2010) either coded EE assessment, used a single question to assess guilt and shame, or used the TOSCA. According to Cherry's review (2017) the literature aligns with our findings that EOI was positively associated with shame and guilt, while CC was positively associated with shame but not guilt. However, the cross-sectional nature of this and previous studies prevents understanding the directional nature of the association without further research.

Our findings align with established theories on EE, shame, and guilt. Shame is typically considered maladaptive, often leading to defensive criticism and associations with CC (Tracy & Robins, 2006a), while CC is less related to guilt as it lacks the repair intention (Tangney & Tracy, 2012). Despite CARE-11's adaptive definition, guilt showed a similar association with EOI as shame, indicating that adaptive guilt can become maladaptive. According to the attributional model of EE, guilt may initially motivate supportive behaviours in caregivers, however guilt can become counterproductive if caregivers fail to repair transgressions or have an inflated sense of personal responsibility (Barrowclough & Hooley, 2003; Tangney & Tracy, 2012). The attributions of blame and self-inflated responsibility are deeply intertwined with the experiences of guilt and shame. Delving into how these emotions and attributions jointly influence EE could open new avenues for future research.

Clinical Implications

The reliability and validity of the CARE highlights the crucial role of guilt and shame within caregiving, particularly concerning EOI and CC among caregivers of individuals with mental health needs. While the primary aim of this study was not to establish the CARE scale for clinical use, the measure nonetheless identifies many unhelpful thinking patterns associated with guilt and shame in caregivers. These patterns could be clinically relevant for intervention, highlighting the importance of being attuned to how caregivers experience guilt and shame in relation to their caregiving roles.

Psychologists may recognise that some caregivers initially display supportive behaviours, however these can evolve into efforts to maintain a positive self-image, potentially contributing to EE (Messham, 2014). Distinguishing the emotional drivers of self-judgments (internalised shame) or perceived societal judgments (externalised shame) can inform clinical formulations and interventions with caregivers.

Moreover, even when caregivers act out of genuine concern for their loved one, their feelings of guilt can inadvertently become maladaptive and potentially leading to EOI. Attribution Theory (Barrowclough & Hooley, 2003) suggests this progression may occur in specific caregiving contexts. This is particularly when caregivers fail to adequately repair mistakes made during caregiving or feel an overwhelming sense of responsibility for their loved one's mental health needs.

These findings highlight the importance of developing behavioural skills for meaningful relationship repair, such as expressing sincere contrition when apologising, to prevent caregiving guilt from becoming maladaptive. The tendency to shoulder personal responsibility should also be assessed as it may lead to EOI. Psychologists can use their understanding of these dynamics and associated coping strategies in their assessment, formulation or inventions with caregivers to build a more positive caregiving environment.

Limitations

While this study employed rigorous methodology and yielded significant findings, several limitations must be acknowledged. Firstly, aligning the CARE with Tangney's theory on guilt and shame improved comparability and improved generalisability but excluded maladaptive guilt, a significant focus in the wider literature (Tilghman et al., 2010). Additionally, the assumption of stability for participants in the two-week reliability assessment period, while conventional (Mokkink et al., 2022), has limited the contextualisation of intra-rater agreement outcomes. Incorporating stability assessments or follow-up interviews in future studies could capture variability and facilitate interpretation of results.

Another limitation is the potential for social desirability bias due to the self-report nature of the measure and its focus on morally charged emotions. To illustrate, a scenario meant to evoke guilt—like a relative's decision to call an ambulance—could be seen as either a moral transgression or justified action, complicating guilt measurement. Despite efforts in Phase 1 to mitigate this by focusing on the phenomenological aspects of guilt and shame, participants might still underreport or misrepresent their feelings to conform to perceived moral norms (Robins & Schriber, 2009). Assessing social desirability bias or other confounding variables in cognitive interviews could help interpret results and enhance reliability.

Additionally, the absence of data on individuals who declined participation prevents analysing differences, which perpetuates selection bias and affects representativeness. The inclusion criterion of requiring professional involvement for participation did not account for exclusions where healthcare access is limited by socioeconomic factors. In the predominantly US sample, this likely skewed the participant pool towards higher-educated individuals. Without information on non-participants, the extent of this selection bias is unknown.

Furthermore, the selection bias, combined with the demographic skew towards white, Western, mostly female participants, restricts the ability to generalise the findings to more diverse populations. Research indicates that the experience and expression of guilt and shame vary across cultures and genders (Bedford & Hwang, 2003; Tangney, 1990) and may also differ according to primary mental health needs or EE levels (Hooley, 2007). Given that a large proportion of the sample had high EE, further exploration and cross-validation across diverse demographic contexts, diagnostic categories and EE levels are needed to ensure the ecological validity and generalisability of the CARE-11.

Future Research

This study established an acceptable level of reliability and validity for the CARE and identified areas for refinement in future validation studies, which have been discussed elsewhere and are summarised here.

Future research should focus on improving intra-rater agreement by providing clearer definitions for the middle categories of the Likert scale. Adopting a mixed-methods approach to incorporating stability and social desirability assessments through follow-up interviews with a subset of participants, could facilitate data triangulation and cross-validation. These enhancements are likely to identify confounding variables, thereby bolstering reliability scores to potentially extend the use of the CARE to clinical settings.

To further enhance structural validity, greater adherence to operational definitions is recommended. For instance, items 6b, 2a, and 3b may capture internalised shame with the inclusion of an avoidance urge. Furthermore, revising scenarios 1a and 11a to involve a caregiver's transgression could more effectively elicit a guilt response, thereby distinguishing it from self-inflated responsibility.

Future CFAs should use methods that accommodate non-linearity to evaluate blame, given its importance to CC (Rothwell, 2023) and consider the role of the attributions related to 'self-inflated responsibility'. Extending the length of both shame dimensions to form their own subscale would also improve internal consistency and unidimensionality.

Abma and colleagues (2016) suggest that hypotheses for construct validity should prioritise variables likely to demonstrate strong associations rather than weak correlations. For instance, when assessing the convergent validity of CARE-guilt, measures of empathy or responsibility-taking attributions will indicate more meaningful insights into the scale's measurement properties than constructs such as anxiety, depression, or self-esteem (Watson et al., 2017). Future hypotheses should reflect this consideration.

To enhance the generalisability of CARE, future studies should address potential selection biases by collecting data from non-participants or applying weighting adjustments in statistical analyses to account for demographic, diagnostic or EE differences. Employing stratified or quota sampling methods could ensure more representative and diverse samples, thereby enhancing the external validity of the findings.

Given the predominantly cross-sectional studies in current literature, further research is needed to understand the directional nature of how guilt and shame in caregiving relate to EE. Longitudinal studies are crucial for clarifying these potentially causal relationships and developing effective family interventions.

Conclusion

This study significantly contributes to the field by validating the CARE-11, a specialised measure for assessing the shame and guilt experienced by caregivers of individuals with enduring mental health needs. The rigorous methodology confirmed that the CARE-11 meets core COSMIN criteria: content validity, internal consistency, and robust internal structure. Cognitive interviews ensured the scale accurately reflects caregivers' complex emotional experiences and aligns with established theoretical constructs of adaptive guilt and multidimensional shame. Future studies could further develop this robust and reliable tool by refining Likert scale categories to reduce inter-rater measurement error.

The CARE-11 provides a nuanced understanding of guilt and shame in the context of EE, surpassing the limitations of traditional dispositional measures. Its specificity to the caregiving context captures the unique emotional challenges faced by informal carers, offering valuable insights for research and clinical practice. The distinction between guilt and shame provides a clearer framework for understanding the emotional dynamics contributing to EE, with implications as a primary objective in caregiver interventions.

In conclusion, the validation of the CARE-11 marks a critical step toward improving our understanding and support of mental health caregivers and their loved ones.

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Appendix A

Modifications Based on Expert Feedback

In alignment with COSMIN guidelines (2017), a comprehensive evaluation of the CARE scale was conducted through interviews with four subject-matter experts and five experiential experts. These interviews provided critical insights that informed a series of modifications aimed at enhancing the scale's content validity and interpretability. Key revisions focused on improving the clarity and conceptual differentiation between guilt and shame, refining scenarios to better align with mental health contexts, and ensuring that the language used was sensitive, inclusive, and free from stigma. Additionally, adjustments were made to reduce respondent discomfort, enhance the scale’s applicability across diverse caregiving contexts, and improve overall readability. These modifications were grounded in widely-accepted theoretical models and were designed to ensure that the CARE scale accurately captures the complex emotional experiences of caregivers while remaining accessible and relevant to a broad audience.

Summary of Modifications to the CARE

Instructions and Orientation

The instructions were revised to provide clearer contextualisation, ensuring participants understand the purpose and focus of the questionnaire. As participants' views can change over time the instructions now emphasise that responses should reflect participants' current perspectives. Items were presented as hypothetical cognitions or feelings, aligning with the intention to capture respondents’ thoughts and emotions.

Content and Clarity Enhancements

A major focus of the modifications was on improving the clarity and conceptual differentiation between guilt and shame. Operant definitions were refined to clearly distinguish these emotions. For instance, Tangney's (1996) definition of guilt, which emphasises the urge to repair relationships following a perceived transgression, was adopted to maintain conceptual clarity. Similarly, the multidimensional aspects of shame were addressed by distinguishing between internalised and externalised shame, drawing on Gilbert's (2003) work on the evolutionary and functional distinction between the emotions. To maintain focus on internal, self-conscious experiences, items related to stigma, particularly those assessing shame experienced from others, were removed.

Scenario Adjustments

The scenarios within the CARE scale were revised to reflect a broader range of mental health caregiving scenarios. For example, a scenario originally focused on medication management was revised to reflect concerns about missed mental health appointments, ensuring participants correctly interpret the context. This change was necessary as some participants initially misinterpreted the scenario as related to physical health rather than mental health management. Moreover, other scenarios perceived as extreme, stigmatising, or implying blame for mental health difficulties were either revised or removed. This was done to ensure neutrality, reduce potential bias in responses, and protect participants from distress. Additionally, certain scenarios were adjusted to explicitly highlight situations where carers perceived they had done something wrong in their caregiving role, better distinguishing feelings of guilt from an inflated sense of responsibility.

Focus on Cognition and Emotion

This was done to ensure that these emotions were accurately represented without implying moral judgment or conflating them with other emotional responses, such as blame. The language was refined to emphasise the internal cognitive processes and emotional responses involved in caregiving. For example, guilt-related responses were updated to express personal responsibility and the desire to repair situations, rather than simply assigning blame.

Additionally, responses across the scale were revised to more precisely reflect the intended emotions, including guilt, blame, externalisation, internalised shame, and externalised shame. These updates ensured that the responses aligned with the revised scenarios and provided a clear and accurate depiction of the carer’s hypothetical thoughts and feelings in various caregiving situations.

Language and Sensitivity Enhancements

To broaden the scale's applicability and ensure inclusivity, diagnostic and medically oriented language was removed or revised. Improvements were also made to the overall readability of the questionnaire, simplifying and refining content to make it easier for participants to understand and complete. In addition, gender-specific terms like "he/she" were updated with gender-neutral language to further promote inclusivity.

Scenarios were adjusted to better align with mental health contexts, avoiding terms that could be perceived as judgmental or stigmatising. Potentially distressing scenarios were also carefully revised or removed. For instance, one scenario originally described a relative attempting to harm themselves, which could be distressing for respondents, especially those with lived experience of similar situations. This scenario was adjusted to avoid explicitly mentioning self-harm while still acknowledging the gravity of the situation. By framing the scenario in terms of the relative's expression of distress and potential actions that might impede their recovery, it maintains relevance to the challenges caregivers may face without overwhelming the respondent.

Applicability and Relevance of Scenarios

The CARE scale's scenarios were further refined to ensure broader applicability across various mental health contexts. This included modifying scenarios to be more relevant and comprehensive, extending the scale's reach beyond psychosis-focused caregiving to a wider range of mental health situations. These revisions aimed to maintain neutrality while accurately capturing the cognitive and emotional responses of caregivers, thereby enhancing the scale's relevance and effectiveness.

Appendix B

Further Analyses

EE Levels Across the Sample

According to the cut-off points established by Wiedemann and colleagues (2002), 199 out of 239 participants (83.26%) who completed the FQ were classified as having high EE, based on scores above 23 for EOI or above 27 for CC. Specifically, 183 caregivers (76.57%) exceeded the threshold for high EOI (23 points), and 134 caregivers (56.07%) for high CC (27 points). Among these, 118 (49.37%) scored highly on both EOI and CC, 16 (6.69%) scored highly on CC but not on EOI, and 65 (27.20%) on EOI but not CC.

Measurement Properties of Blame

Implications of Excluding Blame

As described in the empirical paper, an outcome of the PCA was the exclusion of the externalisation and blame subscales to meet linearity assumptions. Externalisation was removed due to a minimal contribution to the overall scale and weak relationships to other variables in this study (see Table B1 below) and in previous validity assessments (Messham, 2014). This exclusion has streamlined the CARE-11 to be more targeted and efficient to complete. However, the removal of the blame subscale raises important considerations.

Blame, a defensive projection linked to shame, is central to high EE households (Barrowclough & Hooley, 2003; Brown, 2004; Tracy & Robins, 2006b). Rothwell (2023) identified blame as the only significant predictor of CC. Despite its relevance, blame may not have conformed to the linear structure of other self-conscious emotions in the PCA, as it is primarily an attribution rather than a distinct emotional state (Barrowclough et al., 1996).

While theoretically sound, the removal of blame from the measure may critically undermine the measure's utility in predicting overall EE, as blame had a larger association with EE than guilt or shame (See Table B1). Future studies should address the unresolved role of blame through CFA methods that accommodate non-linearity; however, the validity properties of blame are outlined below to substantiate its use at present.

[Insert Table B1]

Reliability

Internal Consistency. The internal consistency of the CARE subscales was evidenced by Cronbach's alphas, categorised as good for guilt ($\alpha = 0.89$), shame ($\alpha = 0.88$); blame ($\alpha = 0.89$); and acceptable for externalisation ($\alpha = 0.76$) (George & Mallery, 2020). Removing individual items did not improve alphas and all were within the acceptable range of 0.70 to 0.95, indicating no redundant items (Tavakol & Dennick, 2011; Terwee et al., 2007).

Test-Retest Reliability. To assess test-retest reliability, Time 1 scores were compared with Time 2 scores, measured at least two weeks apart. The results, in Table B2, revealed very strong correlations, indicating an acceptable level of reproducibility for Blame. High Spearman’s rho values suggest the instrument consistently identifies high and low scorers, supporting its stability for repeated measurements.

[Insert Table B2]

Hypothesis Testing for Construct Validity

Results presented in Table B1 demonstrate the relationships of the blame subscale with the variables: current state of guilt and shame, proneness to emotions, and EE.

Convergent Validity Properties. For convergent validity, the relationships with shame and proneness to externalise are of interest as blame is considered an externalising attribution that regulates shame (Tracy & Robins, 2006). Blame showed significant moderate associations with caregiving shame and proneness to externalising. Although these relationships were only moderate, this was expected as the constructs are related but dissimilar. According to COSMIN criteria (Prinsen et al., 2018), these findings provide adequate evidence of convergent validity for the blame subscale.

The associations between blame and both shame proneness and state shame, though significant, were negligible and weak, respectively. This suggests that these constructs are not sufficiently related to caregiving blame to demonstrate convergence. This unexpected outcome may indicate that the TOSCA and SSGS were too general to capture the relationship with blame, as they are related but distinct emotions (Abma et al., 2016). Future research should focus on establishing associations between blame and more closely related constructs, such as specific measures of blame or other attributional measures.

Predictive Validity Properties. The relationship between blame and the FQ was quantified through correlational analyses. The relationship with CC was expected to be strong, as blame has been shown to be a strong predictor of CC in previous research (Messham, 2014; Rothwell, 2023). As blame serves no reparative function, it was not expected to be associated with EOI.

Results in Table B1 show that blame had a strong positive relationship with CC. A Fisher's Z test indicates that the relationship of blame and CC was significantly larger than those for shame and guilt, $z = 3.23, p < 0.001$, indicating that amongst the CARE subscales, CC has the strongest relationship to blame. This was expected and is consistent with previous research (Messham, 2014; Rothwell, 2023). Therefore, as the correlation with CC exceeds the minimum standards outlined by COSMIN (>.50; Mokkink et al., 2017) the blame subscale has strong predictive validity properties with CC.

However, blame showed moderate positive correlations with EOI. A Fisher's Z test indicates that this correlation was not significantly smaller than that for guilt, $z = 1.48, p = .14$, but was significantly smaller than that for shame $z = 2.28, p = 0.02$. This indicates that, as expected, EOI has the weakest relationship with blame and this subscale is not an adequate predictor of EOI.

Summary of Measurement Properties for Blame

In addition to the content validity established in Phase 1 of the empirical study, the blame subscale demonstrates acceptable internal consistency, test-retest reliability, convergent validity, and predictive validity. According to COSMIN (Mokkink et al., 2010), content validity is the most important measurement property, followed by the internal structure of the instrument, with test-retest reliability and construct validity ranking third in importance. The strong internal consistency of the blame subscale provides part of the evidence of an acceptable internal structure. However, as discussed in the empirical paper, further non-linear assessments are needed to confirm the overall structural validity of the CARE. The positive results in test-retest reliability and construct validity, supported by convergent and predictive validity, strengthen the overall validity of the blame subscale.

Table B1

Spearman's Rho Correlations of CARE-11 subscales, Including Blame and Externalisation, with Measures of EE, State Guilt and Shame, and Proneness to Guilt and Shame.

					CARE-11 subscale			
Measure	Subscale	*n*	*M*	*SD*	Guilt	Shame	Blame	Ext
Caregiving emotions (CARE-11)	Guilt	251	35.2	10.0	-	.78**	.11	-.11
	Shame	251	29.5	10.9	.78**	-	.36**	-.19**
	Blame	251	28.3	10.0	.11	.36**	-	-.02
	Ext	251	38.6	7.9	-.11	-.19**	-.02	-
EE (FQ)	EOI	239	30.5	5.7	0.40**	.46**	.28**	-.03
	CC	239	24.2	6.8	0.14*	.35**	.58**	-.15*
State emotions (SSGS)	Guilt	251	11.6	5.6	0.42**	.48**	.27**	-.02
	Shame	251	12.1	5.6	0.41**	.49**	.26**	.04
Proneness to emotions (TOSCA-3)	Guilt	219	46.5	6.1	0.32**	.25**	.16*	.09
	Shame	199	36.8	9.6	0.51**	.55**	.18**	-.13
	Detached	182	26.1	6.9	-.03	-.05	.14	.31**
	Externalise	174	21.3	6.7	.1	.18*	.32**	.23**

Note. Ext = externalisation subscale of the CARE. For all measures, lower scores indicate lower levels of the measured variable.

* $p < .05$; ** $p < .001$

Table B2

Spearman's Rho Correlation Coefficient at Time 1 and Time 2 for CARE-11 Subscales

	Time 1					
	Guilt	Shame	Internalised Shame	Externalised Shame	Blame	Extern-alisation
Time 2						
Guilt	.82***	-	-	-	-	
Total Shame	-	.83***	-	-	-	
Internalised Shame	-	-	.75***	-	-	
Externalised Shame	-	-	-	.83***	-	
Blame	-	-	-	-	.73***	
Externalisation						.72***

Note. N = 51.

*** *p* < .001

Appendix C

The CARE-11 including the guilt, shame and blame subscales and the updated Likert categories. The subscale label is included for reference only and must be removed prior to use.

CARE-11 Questionnaire

Instructions

- Below is a list of situations relatives tell us they have experienced. They may or may not have happened during the time you have cared for your relative.
- For each situation we have listed four possible responses. Please indicate how likely it is you would have this response *if the situation occurred today.*
- You may think or feel multiple responses to each circumstance so please tell us how likely it is that each of the statements would cross your mind if this situation occurred today. Please tick the most appropriate box for each response.
- There are no right or wrong answers, we are just looking to understand how relatives in a caring role think and feel about these kind of events.
- All your scores are anonymous.
- Please complete all ratings for the responses a) to d), for all questions.

In the following scenarios, how likely is it you would think or feel the following responses *(if the situation occurred today)*…						
1) Your relative doesn’t attend an appointment with mental health services (psychiatrist, psychologist, nurse or other mental health professional)…		Never	Rarely	Possibly	Likely	Very Likely
Guilt	a) I would worry if this was down to me and the times I may not have supported them as well as I would like.	1	2	3	4	5
Blame	b) I would think about how my relative should be taking more responsibility for their treatment so that they can be as well as possible.	1	2	3	4	5
Shame ext.	c) I would worry people think I am not a good carer.	1	2	3	4	5
2) Your relative experiences a period of relapse.		Never	Rarely	Possibly	Likely	Very Likely
Shame ext.	a) I would feel like I’m a failure.	1	2	3	4	5
Guilt	b) I would feel bad about the times I might have helped more but didn’t and think about ways I could make this up to them.	1	2	3	4	5
Blame	c) I would think about how they could have avoided this and should learn to look after themselves better.	1	2	3	4	5
3) You have other commitments (such as work or to other people) alongside caring for your relative, and their mental health deteriorates.		Never	Rarely	Possibly	Likely	Very Likely
Blame	a) I would think about how they need to learn to look after themselves better.	1	2	3	4	5

Shame, int.	b) I would think I am selfish for leaving them.	1	2	3	4	5
Guilt	c) I would feel bad that I prioritised other commitments and would try to make amends.	1	2	3	4	5
4) You attend an appointment with a psychiatrist, psychologist, nurse or other professional, and your relative discusses how they have been feeling worse recently.		Never	Rarely	Possibly	Likely	Very Likely
Blame	a) I would think about how my relative didn't try to help themselves as much as they could have.	1	2	3	4	5
Guilt	b) I would feel bad about my role in this and think about what I could do to help them.	1	2	3	4	5
Shame ext.	c) I would feel like all eyes are on me.	1	2	3	4	5
5) Your relative shares their intention to harm themselves or set back their recovery in some way.		Never	Rarely	Possibly	Likely	Very Likely
Blame	a) I would think they should have asked for help earlier if they were becoming this distressed.	1	2	3	4	5
Shame ext.	b) I would feel as if I have failed.	1	2	3	4	5
Guilt	c) I would wonder if there was something I missed or did wrong and try to find a way to make up for it.	1	2	3	4	5
6) Your relative blames you or your family for their mental health difficulties.		Never	Rarely	Possibly	Likely	Very Likely
Guilt	a) I would think about how they might be right, I could have done	1	2	3	4	5

	things differently and will try and change how I do things in future.					
Shame, int.	b) I would feel like I'm not good enough and want to end the conversation.	1	2	3	4	5
Blame	c) I would think they should look at their own role in their mental health difficulties.	1	2	3	4	5
7) When talking to your friend your relative's mental health difficulties come into the conversation.		Never	Rarely	Possibly	Likely	Very Likely
Blame	a) I would raise the things that my relative is not doing to improve their situation.	1	2	3	4	5
Shame, int.	b) I would feel small and avoid the topic.	1	2	3	4	5
Guilt	c) I would think about what I should do differently in order to help support my relative when they are distressed.	1	2	3	4	5
8) During a conversation with your relative they became angry/upset…		Never	Rarely	Possibly	Likely	Very Likely
Guilt	a) I would think about where I went wrong and show I am sorry that I upset them.	1	2	3	4	5
Blame	b) I would think they shouldn't be so sensitive and have better control over their emotions.	1	2	3	4	5
Shame, int.	c) I would think other families seem to manage without having these problems, why can't we?	1	2	3	4	5
9) You notice that you've been less patient with your relative's mental health difficulties recently…		Never	Rarely	Possibly	Likely	Very Likely

Shame, int.	a) I would feel not good enough so avoid thinking about it.	1	2	3	4	5
Guilt	b) I would feel bad about this and would like to do something to make them feel better about it.	1	2	3	4	5
Blame	c) I would think if they hadn't have behaved this way then I wouldn't have become impatient.	1	2	3	4	5
10) Your relative has been struggling to take care of their own basic needs such as; washing themselves, wearing clean clothes, changes in eating or sleep patterns, and so on…		Never	Rarely	Possibly	Likely	Very Likely
Shame ext.	a) I would think about how other people will judge me because of this.	1	2	3	4	5
Blame	b) I would think they can do these things for themselves; they are just not doing what they should.	1	2	3	4	5
Guilt	c) I would think about the times where I could have supported their independence but didn't and plan how to change this.	1	2	3	4	5
11) Your relative's symptoms deteriorate and you decide to ring services (e.g. the local mental health team, emergency services), even though your relative has not asked you to call.		Never	Rarely	Possibly	Likely	Very Likely
Blame	a) I would think my relative could have prevented this from happening and then I wouldn't have had to call.	1	2	3	4	5
Guilt	b) I would feel bad for not asking for their permission and think about how we can repair this.	1	2	3	4	5

Shame, int.	c) I would feel small for not being able to care for my relative without help.	1	2	3	4	5

Section Three: Critical Appraisal

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Overview of Thesis

This thesis has considered the emotional strain of mental health caregivers and contributed to the research understanding of the emotional drivers behind expressed emotion (EE). Despite this being considered an important area in mental health research, guilt focused interventions have a stronger evidence base in dementia caregiving literature. A systematic search across both fields revealed limited interventions within a mental health context and only a few in the dementia literature where guilt was a primary objective. The evidence base was summarised in a systematic literature review (SLR) to identify the research directions needed to establish a robust evidence base which may guide mental health caregiver interventions. The SLR highlighted that addressing the beliefs underlying guilt was a key strategy of effective interventions. Appraisals of the evidence base and available measures revealed there was no appropriate and validated measure to assess guilt interventions for caregivers in a mental health setting.

The Care And Related Emotions scale (CARE), designed to assess shame and guilt among mental health caregivers, had not yet been validated. This measure, derived from Attribution Theory and EE research, has potential for evaluating mental health caregiver interventions. Thus, the empirical paper adhered to COSMIN guidelines to establish the reliability and validity of the CARE. Key measurement properties—including content, structural validity and reliability—were validated, in addition to convergent validity and unidimensionality. While these properties confirm the CARE is appropriate for research purposes, COSMIN recommend supplementary analyses that revealed clarification of the Likert scales could enhance reliability. Encouragingly, predictive validity assessments demonstrated specific associations of guilt and shame with EE constructs, EOI and CC. With the CARE scale validated as a reliable and insightful tool for measuring the emotional experience of caregivers, this critical appraisal outlines the measure's limitations in applications of future research.

A key priority of COSMIN was to establish content validity through feedback obtained from interviews with subject area professionals and caregiver experts. This process refined the CARE and aligned it with widely-accepted theoretical constructs that guilt as an adaptive response to making a transgression and conceptualise shame as a multidimensional emotion, incorporating both internalised and externalised aspects (Gilbert, 2003; Tangney & Dearing, 2002). These revisions enhanced the relevance and comprehensiveness of the CARE measure, and the implications of the changes will be considered.

Aligning the CARE measure with the wider literature base has provided an opportunity to develop further insight into how specific aspects of guilt and shame may relate to EE. Subsequently, the final part of the critical appraisal will examine how the CARE can inform our understanding of EE and attribution theory. This understanding will build on the findings of the SLR by identifying the underlying beliefs that future research may address in caregiver interventions. Additionally, this framework speculates on hypotheses for clinicians to consider when developing formulations.

Limitations and Future Research

Selection Bias and Missing Demographic Information

This study provides valuable insights into the emotional dynamics of caregiving, yet several limitations must be acknowledged to contextualise the findings and guide future research using the CARE. A significant limitation is the potential for selection bias due to the recruitment strategy used. Participants were primarily recruited through social media carer groups, which may attract individuals who are more motivated or already have sufficient support. This method favours those with access to technology, potentially excluding caregivers who lack these resources or are less familiar with online platforms. Consequently, the sample may differ demographically from the broader carer population in terms of age, socio-economic status, and support networks, potentially skewing the results towards those with higher education, technological access, and greater social support (Hargittai, 2020). The absence of data on non-participants also complicates the assessment of the sample's representativeness.

Another limitation is the omission of key contextual factors, such as the length of caregiving, the duration of the loved one's illness, and the availability of resources and support. These variables are central to understanding the diversity of carer experiences, as they impact emotional resilience, coping strategies, and the caregiving burden (Litzelman et al., 2020; Ory et al., 1999; Schulz & Martire, 2004). Notably, carers with the greatest needs—those who are isolated, overburdened, or lacking support—are often the least likely to participate in research, despite being the very individuals whose experiences are most important to understand and represent (Oliver et al., 2020; Smith et al., 2014). Without these data it is difficult to assess if the CARE captures an adequate range of caregiving experiences and suggests future research should incorporate more comprehensive demographic questionnaires.

Cognitive Interviews

Cognitive interviews were used to assess whether the CARE is comprehensive, appropriate and comprehensible. These interviews refined the measure but also highlighted challenges in establishing error, particularly for factors such as social desirability bias either due to impression management or self-deception (Tourangeau & Yan, 2007). Social desirability bias may have been particularly pronounced for this study given that guilt and shame are tied to moral standards (Tangney, 1996). Although cognitive probes are designed to detect if such errors are in the CARE survey (Willis, 2004), identifying these biases during these interviews themselves proved challenging, possibly due to interviewer's inexperience. Consequently, it is unclear whether participants tailored their responses to align with perceived societal expectations, potentially obscuring their true feelings.

For instance, two caregivers hesitated to provide feedback that may lead to changes in the measure, despite reassurance that driving change was a key objective of the interview. Given that these interviews were conducted later in the process, it is also possible that fewer flaws remained to be detected. Moreover, there is no evidence to suggest additional interviews would have uncovered more issues (Blair & Conrad, 2011) and as the sample size used is sufficient according to COSMIN guidelines (Terwee et al., 2018), an appropriate balance of reliability and practicality was achieved. Nonetheless, the presence of error from factors such as social desirability bias may have limited the feedback gained from cognitive interviews.

In addition to social desirability bias, sensitive emotions such as shame and guilt are often protected by complex defence mechanisms (Tangney, 1996; Tracy & Robins, 2006), indicating unconscious self-deception could be a factor. This adds another layer of complexity to the cognitive interview process, making it difficult to ascertain whether participants were fully aware of, or able to articulate, their true emotional responses. This was highlighted when one caregiver demonstrated higher mentalisation and emotional literacy than others, as evidenced by their ability to articulate their multifaceted emotional responses to items on the CARE. As mentalising abilities vary across the population and are affected by emotional arousal (Fonagy & Bateman, 2008; Weinstein et al., 2022), this could be a confounding variable influencing the quality and depth of the feedback provided. To assess whether these issues impact the quality of cognitive interviews, future studies exploring complex emotions may benefit from incorporating assessments of emotional awareness or reflective functioning (a measure of mentalisation) to determine the presence of such effects.

Future research may also wish to consider including the care recipient's perspective in cognitive interviews. While this study focused on caregivers' experiences, a more comprehensive understanding of the caregiving relationship would be gained through involvement of both parties. As discussed above, all feedback is inherently limited by awareness (Latkin et al., 2017), which extends to relational dynamics in caregiving. Feedback from care recipients could offer valuable context for interpreting caregivers' emotional responses and attributions, enriching the depth of the CARE. For instance, care recipients may add to the scenarios' specific details about their circumstances that they have noticed cause caregiver distress. They may also assess the realism of the relational dynamics presented. Although beyond our study's scope, involving care recipients could enhance the CARE measure's applicability by offering a more comprehensive view of the relationship.

Future Directions and Methodological Considerations:

To address these limitations, future recruitment strategies should be more inclusive and widely disseminated to capture a more diverse range of caregiver experiences. Intentional outreach through community organisations, healthcare providers, or direct contact methods that do not rely on technology will be essential for reaching underrepresented caregivers. Future research should consider employing mixed-methods approaches, combining quantitative and qualitative data to capture the complexity of caregiving experiences. Follow-up interviews with a selection of participants, and possibly relatives, could provide additional depth and help validate quantitative findings. Moreover, using trained interviewers and incorporating measures of emotional literacy or mentalisation could enrich the analysis, providing a clearer picture of how caregivers process and articulate their emotions. Triangulating findings and identifying potential confounding variables, will better position the CARE to accurately reflect the diverse challenges faced by carers in different contexts.

Theoretical Implications

Implications of Changing The CARE

As previously discussed, interviews with professional experts led to significant revisions in the measurement of guilt and shame within the CARE. Guilt and shame, being co-occurring constructs, present challenges in measurement; however, a key strength of this study was the alignment of the guilt construct with more established theoretical evidence using an adaptive definition (Tangney & Dearing, 2002). This alignment was crucial because guilt and shame, despite their overlap, have distinct evolutionary roots (Gilbert, 2003). By refining the guilt construct, the study not only reduces the heterogeneity of the evidence base but also enhances the face validity of the measure. This step ensures that the measure is theoretically robust and more accurately reflects the construct it intends to assess.

Moreover, the study's incorporation of a multidimensional construct of shame stands as another significant strength. The revised shame subscale now clearly differentiates between internalised and externalised aspects of shame. This distinction is critical because externalised shame, associated with stigma and fear of public exposure, contrasts with internalised shame, which involves negative self-judgements typically stemming from significant attachment figures and is closely tied to the individual's self-concept (Gilbert, 2003). Furthermore, understanding these distinctions may also offer deeper insights into how specific aspects of guilt and shame relate to EE, particularly EOI and CC, as discussed later.

However, to establish the structural validity of CARE, and ensure the scale could distinguish between shame and guilt, it was necessary to remove the blame and externalisation subscales during the Principal Components Analysis (PCA). As discussed in the empirical paper, these subscales measure attributions and not emotions, and their inclusion was disrupting the linearity assumption of the PCA and preventing the assessment of structural validity. While this decision was theoretically sound—given that attributions are distinct from emotions—it may have inadvertently reduced the CARE’s association with EE. This is particularly important, as the blame subscale has been identified in previous research as a significant independent predictor of CC (Rothwell, 2023) and, in the present study, exhibited the strongest association with EE. This suggests that its removal might have attenuated the overall relationship between CARE and EE.

The externalisation subscale, though less likely to impact the measure's relevance to EE, still represents a potential loss in capturing the full scope of the caregiving experience. One caregiver expert highlighted the value of the original four-subscale structure, noting that it offered multiple potential responses to the same scenario. This allowed the caregiver to recognise a tendency to attribute blame to their relative rather than acknowledging their own role in a disagreement. Such reflections could foster a deeper understanding and potentially lead caregivers to monitor and change their responses to distress. This suggests the original measure served not only as a valuable research tool but also as a means for promoting self-reflection among caregivers.

Therefore, while the removal of the externalisation and blame subscales has streamlined the CARE measure and improved its focus on emotions, this refinement may have diminished its clinical impact and relevance to EE research. Given that blame is a significant predictor of CC, future studies may benefit from using this subscale. To support this, evidence of content validity, internal consistency, test-retest reliability, and construct validity properties of the blame subscale are included in the appendix, endorsing its inclusion in future research. This approach balances the need to establish structural validity by distinguishing between guilt and shame with the practical considerations of research and clinical application, ensuring that the measure remains both valid and relevant.

Attribution Theory, EE and the CARE

As this thesis has demonstrated, caregiving within the context of mental health presents complex emotional challenges that significantly impact both the caregiver and the care recipient. While the primary role of the thesis was to consider the role of guilt and shame in the EE caregiving literature, the SLR highlighted the positive outcomes of addressing underlying beliefs in interventions. The findings of the empirical study, which aimed to establish the validity properties of the CARE measure, are contextualised within the broader literature on attribution theory and EE. With the CARE now positioned to inform intervention strategies, it becomes necessary to deepen the understanding of how the attributions and beliefs underlying guilt and shame interrelate to various aspects of EE. This enhanced understanding could be used by clinicians to inform their formulations yet also has the potential to guide further research.

The subsequent outline of how the CARE emotions relate to EE and attribution theory builds upon the findings of both the SLR and empirical paper to illuminate key beliefs that could be addressed in future caregiver interventions. To support interpretations, additional correlational analyses between CARE items and FQ items were conducted. These correlations are speculative as they lack sufficient power to draw definitive conclusions, however they provide exploratory insights and suggest potential patterns regarding differences in attributional profiles. This is a hypothesised framework and a corresponding flowchart is presented as Figure 1.

Attribution Theory

Attribution theory offers a valuable framework for understanding caregiver responses, as caregivers frequently attribute their relative’s difficulties to specific causes that influence our emotional responses (Barrowclough & Hooley, 2003; Weiner, 1986). These causes can be categorised as internal or external, specific or global, stable or unstable, and controllable or uncontrollable. These attributions significantly influence the caregiver's emotional responses and subsequent behaviours. For instance, when a caregiver attributes a situation to internal, specific, unstable, and controllable factors, guilt is likely to arise (Barrowclough et al., 1996). This type of guilt is characterised by a sense of personal responsibility for the situation, accompanied by the belief that it can be rectified (Tangney, 1996). While such guilt may initially motivate corrective actions, CARE guilt is also a significant predictor of EOI (Rothwell, 2023), suggesting attempts to cope with the emotion can lead to adverse outcomes.

The Guilt Attribution Profile: Internal/specific/controllable Causes

To understand how guilt can become maladaptive, it's important to consider the definitions and limitations of the CARE measure and how these may hinder an accurate assessment of the emotion. The CARE measures thoughts that represent emotions, but not emotions themselves, which, as discussed earlier, may be influenced by the respondent's emotional awareness and mentalisation abilities. Additionally, it is a self-report measure that evaluates responses to hypothetical scenarios. Although guilt-driven repair typically involves actions like apologising, undoing, or expressing remorse (Tangney, 1990), the CARE's guilt items capture only the intention to repair, not how they repair.

Without clear steps defined for repair, it is possible that the association between repair attempts on the CARE and self-sacrifice items on the FQ suggests that caregivers may consider these actions an adequate form of repair. This is concerning because self-sacrifice can be detrimental to the caregiver and leads to EOI, which is detrimental to the care recipient. Moreover, while self-sacrifice might be perceived as making amends, it does not provide the opportunity to heal the transgression, relieve guilt, or foster bonding, in the way expressions of remorse or contrition would (Tracy & Robins, 2006).

An Additional Guilt Attribution Profile: Internal/Specific/Uncontrollable Causes

Vaughn and Leff (1976) proposed that guilt becomes maladaptive when caregivers feel responsible for their relative's illness. This idea is supported by the attributional model of EE, which suggests that while guilt can initially encourage supportive behaviours, it may become unconstructive if caregivers fail to make adequate reparations or excessively question their role in their loved one's suffering (Barrowclough & Hooley, 2003; Hatfield, 1981; Tangney & Tracy, 2012). This was supported by the FQ and CARE item correlational analyses. Thoughts about causes of a relative's illness were more strongly linked to the guilt items from scenarios where caregivers took responsibility for a transgression and showed more active repair attempts. In these scenarios, the relative tended to be upset or distressed. Additionally, the PCA identified some of these items as distinct from other items on the guilt subscale in Component 3. Collectively, these findings suggest that caregivers who believe they caused their relative's mental health needs, tend to attribute the cause to internal, stable, and uncontrollable factors. The uncontrollable attribution reflects a belief that past events cannot be changed.

From this, a hypothesised pathway emerges. This pathway explains how an internal/specific/uncontrollable guilt attribution profile may lead to EOI. Caregivers who believe they are responsible for their loved one's mental health difficulties may experience an inflated sense of responsibility when they feel confronted by their regrets when witnessing their loved one's woes. This confrontation may trigger a guilt-induced urge to repair and a simultaneous sense of powerlessness, as they cannot change the past. In response, they may attempt indirect repair by neglecting their own needs. However, as Tangney and Tracy (2012) suggest, indirect reparations do not adequately address the underlying causes of guilt. This may trap caregivers in a cycle of indirect repair through self-sacrifice, maintaining or perpetuating EOI. Since care recipients are unlikely to recognise self-sacrifice as an attempt to repair, resolution may not occur. Without resolution, caregivers' worries about their relative, coupled with self-sacrifice, may further drive EOI.

Guilt and CC. Previously, guilt has been considered unlikely to lead to CC, as CC lacks an intention to repair (Cherry et al., 2017). However, this study revealed a significant, albeit small, relationship between guilt and CC. Further examination of the FQ item correlations indicated that the 'active responsibility' guilt items were associated with a sense of 'feeling underappreciated' and conflict. That is guilt may lead to CC when caregivers neglect themselves and feel unappreciated, triggering conflict. As these scenarios shared strong correlations with blame items, which is a significant predictor of CC, when caregivers feel underappreciated they may resort to blaming their relative as a protective mechanism that results in CC (Tracy & Robins, 2006).

The Attribution Profiles of Shame

Shame significantly shapes caregiving responses, with different dimensions influencing behaviour in distinct ways. The correlational analyses of shame items with the FQ suggest that externalised and internalised shame affect EE differently. An evaluation of the literature indicates that externalised shame, which involves the imagined perception of how others view the caregiver's situation, has two distinct attribution profiles in relation to EE.

Externalised Shame Attribution Profile: External/Specific/Controllable Causes

The first profile is characterised by specific, controllable attributions, where caregivers fear being perceived as responsible by others and thus attempt to control outcomes. This form of shame may drive caregivers to neglect their own needs in an effort to conceal their perceived shortcomings and manage their social image (Tangney & Tracy, 2012). Closely tied to stigma, the fear of public exposure, and avoidant attachment, this reflects how some caregivers' efforts to assist their loved one may be driven by a desire to maintain a positive self-image (Cherry et al., 2018; Gilbert, 2003; Messham, 2014). The externalised shame responses were associated with attempts to control relatives and appeared to lead caregivers to neglect themselves, experience sleeplessness, and were inversely related to how important the person was to them.

A Second Externalised Shame Attribution Profile: External/Global/Uncontrollable Causes

The second externalised shame profile involves global and uncontrollable attributions related to perceived shortcomings, such as the belief that "everyone knows I'm flawed." This imagined perception of being publicly exposed as inadequate (in contrast to a flawed action, which is controllable) is typically accompanied by a survival threat related to the fear of exclusion, which is profoundly distressing (Gilbert, 2003). To avoid and protect against this intense discomfort, caregivers may subconsciously deflect blame onto the care recipient, ultimately leading to CC (Rothwell, 2023; Tracy & Robins, 2006). The scenarios that were public or involved externalised shame tended to have higher loadings with irritation, anger and conflict responses of CC. These were also high for blame, suggesting a route to CC (Rothwell, 2023).

The Internalised Shame Attribution Profile: Internal/Global/Uncontrollable Causes

Internalised shame presents different challenges. Caregivers who internalise shame often perceive themselves as fundamentally flawed, attributing their caregiving difficulties and family member's mental health needs to stable, global, and uncontrollable aspects of their character. This emotional state is associated with self-critical thoughts. In the correlational analyses, self-critical thoughts were associated with self-neglect aspects of EOI. Gilbert (2003) suggests that the absence of self-soothing in response to self-criticism may perpetuate internalised shame and activate an overwhelming fear of social exclusion. In such an instance, caregivers would likely defend against this fear of exclusion, as outlined above, by deflecting responsibility for the situation onto their relative, leading to CC. Consequently, internalised shame can lead to EOI as self-criticisms drive self-sacrifice and may also occasionally lead to CC when self-criticisms activate a fear of exclusion and trigger a blame defence.

A Summary of Attribution Profiles

In summary, guilt may be associated with two attribution profiles. When caregivers believe the cause of a situation is internal, specific and controllable, they experience guilt. Guilt is characterised by an intention to repair and, in this study, was associated with self-sacrifice, suggesting caregivers may perceive these are appropriate pathways to repair, despite this leading to EOI. A second attribution profile is proposed for when caregivers believe they caused a loved one's illness, the attribution remains internal and specific but becomes uncontrollable. In these instances, guilt drives repair, through indirect means such as self-sacrifice. Since guilt driven self-sacrifice is unlikely to constitute an adequate repair, this may become a cycle that perpetuates EOI. In some circumstances where continued self-sacrifice leads to caregivers feeling underappreciated, the resulting irritation and anger may lead to blame, contributing to CC.

Caregivers experiencing internalised shame may engage in self-criticism that drives self-sacrifice and leads to EOI. In situations where these self-criticisms are not soothed, they may trigger a fear of social exclusion that drives projection of blame onto their relative and results in CC. In contrast, externalised shame may lead caregivers to believe they are perceived as responsible for their relative's difficulties. If they believe this perception is controllable, they may attempt to maintain their social image by neglecting their own needs, resulting in EOI, or by controlling their relative, leading to blame and then CC. When caregivers believe they are perceived as responsible due to uncontrollable personal flaws, they may unconsciously defend themselves with blame, directly leading to CC.

Future Research

These speculative pathways highlight the role of attributions and their connection to the underlying beliefs of shame and guilt, particularly in relation to responsibility-taking and how this relates to attempts to repair for caregivers. While this hypothesised framework may be useful for clinicians to consider when developing personalised formulations, broader applications could be achieved if these pathways are validated by future research.

A valuable first step would be to conduct in-depth interviews with caregivers and relatives to refine the pathways and assess their relevance. Interviews could explore how attributions and beliefs shape their sense of responsibility, influence emotional responses, and inform coping strategies, especially for non-cohabiting, non-parental caregivers. Understanding their perspectives on repair—whether indirect repair alleviates guilt or if specific conditions are needed for effective guilt reduction—would potentially lead to new insights.

Modifying the CARE to reflect these findings and testing the proposed relationships through hierarchical regressions with the FQ and attributional measures would quantify potential pathways of EE involving guilt and shame. This approach would lay the groundwork for longitudinal studies to clarify the direction of associations identified. With a deeper understanding of the attributions underpinning guilt and shame, future interventions addressing these beliefs could potentially mitigate the impact of EE on families.

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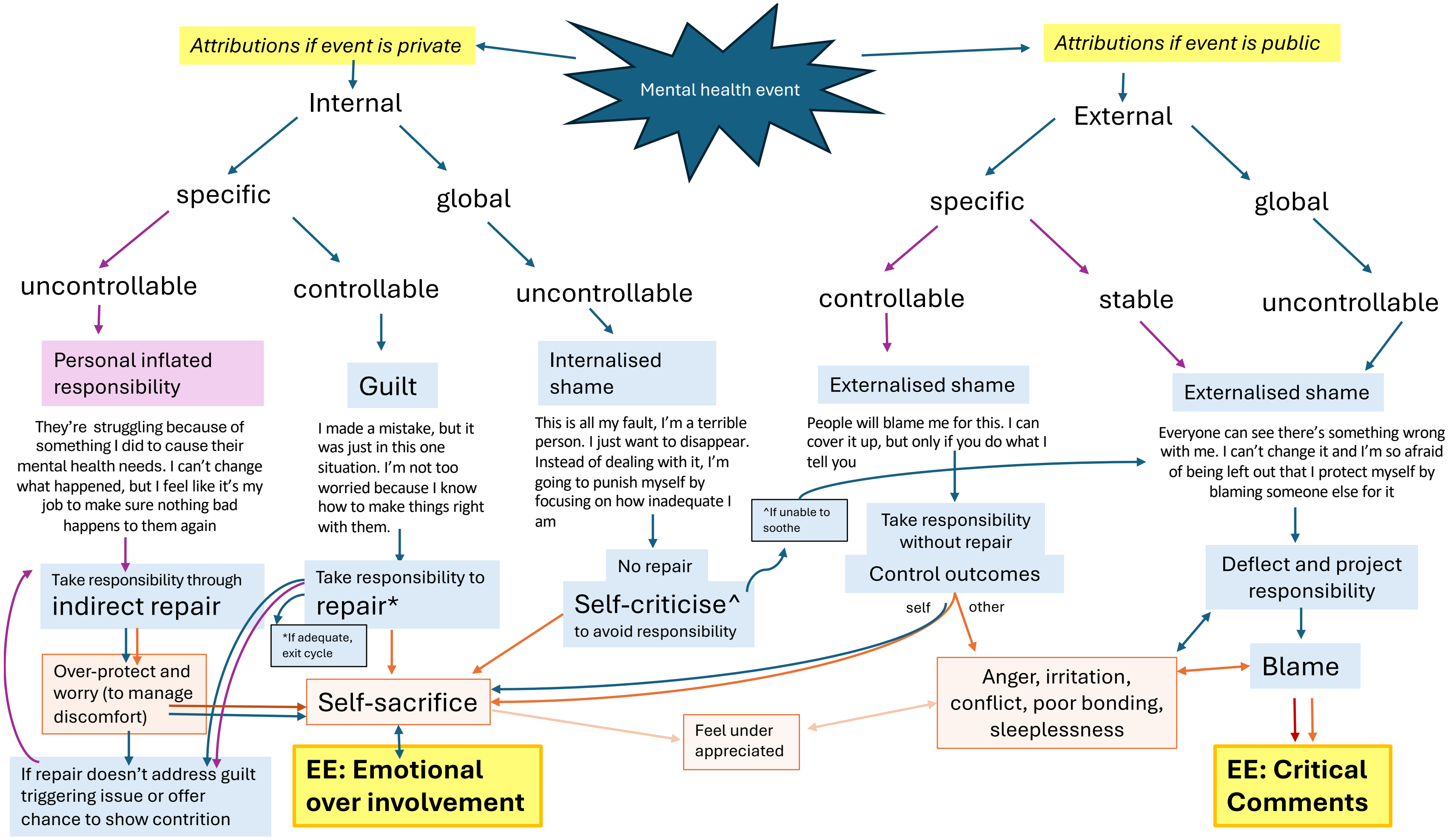
Figure 1

Attributional Pathways That Outline How Guilt and Shame Contribute to EE



They're struggling because of something I did to cause their mental health needs. I can't change what happened, but I feel like it's my job to make sure nothing bad happens to them again

I made a mistake, but it was just in this one situation. I'm not too worried because I know how to make things right with them.

This is all my fault, I'm a terrible person. I just want to disappear. Instead of dealing with it, I'm going to punish myself by focusing on how inadequate I am

People will blame me for this. I can cover it up, but only if you do what I tell you

Everyone can see there's something wrong with me. I can't change it and I'm so afraid of being left out that I protect myself by blaming someone else for it

Key for Figure 1: Attributional Pathways That Outline How Guilt and Shame Contribute to EE

- Blue box – Established theoretical understanding
- Peach box – FQ items that capture components of EE
- Lilac box – Proposed responsibility-taking factor observed in Empirical Paper
- Lilac line – Hypothesised attribution pathways linking guilt, responsibility-taking, repair, and EE
- Blue line – Established theoretical pathway
- Orange line – Proposed pathway supported by associations in Table 1
- Faded orange line – Proposed pathway supported by weak associations in Table 1
- Orange and blue lines – Theoretical pathway supported by associations in Table 1
- Red line – Pathway observed in previous research (Rothwell, 2023), showing Blame is a predictor of CC

Table 1

Correlations Between Guilt Items on CARE and EOI Items of FQ

	EOI items on FQ									
Guilt items on CARE	I tend to neglect myself because of him/her	I often think about what is to become of him/her	I keep thinking about the reasons for his/her illness	I can't sleep because of him/her	When something about him/her bothers me, I keep it to myself	I regard my own needs as less important	I'm very worried about him/her	I thought I would become ill myself	He/she is an important part of my life	I have given up important things in order to be able to help him/her
1) I would worry if this was down to something I did as I didn't support them as I had intended	.158*	0.075	.129*	.185**	.234**	.297**	0.111	.149*	-0.053	0.089
2) I would feel bad about the times I might have helped more but didn't and think about ways I could make this up to them.	.145*	0.08	.192**	.170**	.305**	.361**	.166*	.171**	0.015	0.072
3) I would feel bad that I prioritised other commitments and would try to make amends.	.274**	0.086	.131*	0.018	.301**	.429**	.246**	.138*	.136*	.197**

	EOI items on FQ									
Guilt items on CARE	I tend to neglect myself because of him/her	I often think about what is to become of him/her	I keep thinking about the reasons for his/her illness	I can't sleep because of him/her	When something about him/her bothers me, I keep it to myself	I regard my own needs as less important	I'm very worried about him/her	I thought I would become ill myself	He/she is an important part of my life	I have given up important things in order to be able to help him/her
4) I would feel bad for encouraging them to join me and try to think of ways to be more helpful.	0.105	-0.055	0.099	-0.009	$.202^{**}$	$.230^{**}$	0.015	0.126	0.044	0.012
5) I would feel bad about my role in this and think about what I could do to help them.	$.168^{**}$	0.082	$.215^{**}$	0.125	$.280^{**}$	$.338^{**}$	0.118	$.183^{**}$	0.017	0.094
6) I would wonder if there was something I missed or did wrong and try to make up for it.	0.099	$.139^{*}$	0.056	0.018	$.175^{**}$	$.287^{**}$	$.152^{*}$	0.079	-0.043	0.109
7) I would think about how they might be right, I could have done things differently and will try and change how I do things in future.	$.205^{**}$	0.075	$.236^{**}$	$.139^{*}$	0.112	$.285^{**}$	0.109	$.182^{**}$	0.035	0.088

	EOI items on FQ									
Guilt items on CARE	I tend to neglect myself because of him/her	I often think about what is to become of him/her	I keep thinking about the reasons for his/her illness	I can't sleep because of him/her	When something about him/her bothers me, I keep it to myself	I regard my own needs as less important	I'm very worried about him/her	I thought I would become ill myself	He/she is an important part of my life	I have given up important things in order to be able to help him/her
8) I would go over what I should do differently in order to prevent my relative's distress.	.172**	0.082	.192**	.135*	.226**	.235**	.189**	0.107	0.072	0.007
9) I would think about where I went wrong and show I am sorry that I upset them.	.190**	0.049	.227**	0.112	.294**	.352**	.191**	.135*	0.091	0.107
10) I would feel bad about this and would like to do something to make them feel better about it.	.197**	0.039	.232**	0.109	.167**	.293**	.168**	0.089	0.115	0.076
11) I would feel responsible for not supporting their independence more and think about how I could make up for it.	.259**	0.104	0.094	.189**	.215**	.322**	.165*	0.071	0.012	.131*

	EOI items on FQ									
Guilt items on CARE	I tend to neglect myself because of him/her	I often think about what is to become of him/her	I keep thinking about the reasons for his/her illness	I can't sleep because of him/her	When something about him/her bothers me, I keep it to myself	I regard my own needs as less important	I'm very worried about him/her	I thought I would become ill myself	He/she is an important part of my life	I have given up important things in order to be able to help him/her
12) I would worry if this had damaged the trust in our relationship and think about how to repair this.	.221**	0.099	.224**	.139*	.207**	.224**	0.063	.211**	0.044	0.125
Shame items on CARE										
1) I would worry people think I am not doing a good job as a carer for my relative.	.305**	.204**	.178**	.311**	.229**	.334**	.255**	.191**	-0.021	.223**
2) I would feel like I'm a failure.	.228**	.204**	.163*	.235**	.266**	.425**	.191**	.142*	0.07	.230**
3) I would feel like a bad person.	.269**	0.064	0.125	0.101	.307**	.359**	.129*	.268**	-0.057	.145*
4) I would worry about what people think of me.	-0.033	0.055	0.049	.164*	0.082	0.098	-0.033	-0.022	-.159*	0.019

	EOI items on FQ									
Shame items on CARE	I tend to neglect myself because of him/her	I often think about what is to become of him/her	I keep thinking about the reasons for his/her illness	I can't sleep because of him/her	When something about him/her bothers me, I keep it to myself	I regard my own needs as less important	I'm very worried about him/her	I thought I would become ill myself	He/she is an important part of my life	I have given up important things in order to be able to help him/her
5) I would feel like all eyes are on me.	.230**	-0.008	0.071	.330**	.187**	.287**	.160*	.197**	-0.077	.151*
6) I would feel as if I have failed.	.261**	.201**	.161*	.175**	.308**	.439**	.296**	.194**	-0.006	.283**
7) I would feel like I'm not good enough and want to end the conversation.	.222**	0.045	0.082	0.125	.362**	.233**	-0.027	.212**	-.161*	0.103
8) I would feel small and avoid the topic.	.211**	-0.002	0.048	0.108	.334**	.271**	-0.027	.197**	-0.123	.151*
9) I would think other families seem to manage without having these problems, why can't we?	.181**	.182**	.148*	.216**	.242**	.201**	0.115	.236**	-.144*	.175**
10) I would feel not good enough so avoid thinking about it	.298**	0.109	.194**	0.082	.326**	.295**	.131*	.273**	-0.053	.205**

	EOI items on FQ									
Shame items on CARE	I tend to neglect myself because of him/her	I often think about what is to become of him/her	I keep thinking about the reasons for his/her illness	I can't sleep because of him/her	When something about him/her bothers me, I keep it to myself	I regard my own needs as less important	I'm very worried about him/her	I thought I would become ill myself	He/she is an important part of my life	I have given up important things in order to be able to help him/her
11) I would think about how other people will judge me because of this.	$.152^{*}$	$.192^{**}$	$.137^{*}$	$.218^{**}$	$.237^{**}$	$.231^{**}$	0.08	$.133^{*}$	-0.101	$.226^{**}$
12) I would feel bad that I couldn’t handle this on my own.	$.182^{**}$	0.062	$.210^{**}$	$.153^{*}$	$.251^{**}$	$.285^{**}$	0.103	$.290^{**}$	-0.024	$.166^{*}$
Blame items on CARE										
1) I would think they should be able to control their own actions.	0.025	$.153^{*}$	$.142^{*}$	$.132^{*}$	0.095	0.068	-0.008	$.158^{*}$	-0.041	0.053
2) I would raise the things that my relative is not doing to improve their situation.	0.074	$.219^{**}$	$.156^{*}$	$.135^{*}$	-0.006	0.016	0.071	0.047	-0.028	0.041

	EOI items on FQ									
Blame items on CARE	I tend to neglect myself because of him/her	I often think about what is to become of him/her	I keep thinking about the reasons for his/her illness	I can't sleep because of him/her	When something about him/her bothers me, I keep it to myself	I regard my own needs as less important	I'm very worried about him/her	I thought I would become ill myself	He/she is an important part of my life	I have given up important things in order to be able to help him/her
3) I would think they should look at their own role in their mental health difficulties.	-0.002	0.082	0.036	0.008	0.092	-0.087	-0.021	$.133^{*}$	-0.001	0.011
4) I would think about how my relative should be taking more responsibility for their treatment so that they can be as well as possible.	0.034	$.327^{**}$	0.118	0.046	0.08	0.03	$.204^{**}$	$.145^{*}$	0.025	0.097
5) I would think about how my relative didn’t help themselves as much as they could have.	0.124	$.186^{**}$	$.164^{*}$	$.139^{*}$	0.049	0.073	0.024	$.218^{**}$	-0.102	$.168^{**}$
6) I would think they should have asked for help earlier if they were becoming this distressed.	$.134^{*}$	0.064	0.089	0.026	0.075	0.108	0.12	$.169^{**}$	-0.067	0.124

Blame items on CARE	EOI items on FQ									
	I tend to neglect myself because of him/her	I often think about what is to become of him/her	I keep thinking about the reasons for his/her illness	I can't sleep because of him/her	When something about him/her bothers me, I keep it to myself	I regard my own needs as less important	I'm very worried about him/her	I thought I would become ill myself	He/she is an important part of my life	I have given up important things in order to be able to help him/her
7) I would think about how they could have avoided this if they had just learned to look after themselves better.	0.122	.246**	0.095	0.047	0.065	0.036	0.071	0.086	0.001	0.094
8) I would think about how they need to learn to look after themselves better.	0.065	.147*	0.057	0.046	0.112	-0.008	0.009	0.09	-0.056	0.106
9) I would think they can do these things for themselves; they are just not doing what they should.	.158*	.218**	0.108	0.083	.167**	.132*	0.042	0.094	-0.061	.189**
10) I would think my relative could have prevented this from happening and then I wouldn't have had to call.	.156*	.163*	.185**	.168**	.163*	.157*	-0.003	.183**	-0.12	.187**

Blame items on CARE	EOI items on FQ									
	I tend to neglect myself because of him/her	I often think about what is to become of him/her	I keep thinking about the reasons for his/her illness	I can't sleep because of him/her	When something about him/her bothers me, I keep it to myself	I regard my own needs as less important	I'm very worried about him/her	I thought I would become ill myself	He/she is an important part of my life	I have given up important things in order to be able to help him/her
11) I would think they shouldn't be so sensitive and have better control over their emotions.	0.053	0.01	0.027	0.013	0.066	-0.023	-.131*	0.08	-0.087	0.045
12) I would think if they hadn't behaved this way then I wouldn't have become impatient.	.147*	0.108	0.114	.174**	0.059	0.11	0.024	.185**	-0.059	.151*

Note. Externalised shame items are italicised

Table 2

Correlations Between Blame Items of CARE and CC Items of FQ

	CC items on FQ									
Guilt item on CARE	I have to keep asking him/her to do things	He/she irritates me	I have to try not to criticise him/her	It's hard for us to agree on things	He/she does not appreciate what I do for him/her	He/she sometimes gets on my nerves	He/she does some things out of spite	When he/she constantly wants something from me, it annoys me	I have to insist that he/she behave differently	I'm often angry with him/her
1) I would worry if this was down to something I did as I didn't support them as I had intended	0.089	0.01	.215**	.166*	.170**	0.054	-0.007	0.005	0	0.043
2) I would feel bad about the times I might have helped more but didn't and think about ways I could make this up to them.	0.069	0.05	.261**	.154*	.144*	0.067	0.061	0.05	0.02	0.099
3) I would feel bad that I prioritised other commitments and would try to make amends.	0.107	-0.025	.214**	.162*	0.014	-0.04	-0.054	-0.043	-0.048	0.006

Guilt item on CARE	CC items on FQ									
	I have to keep asking him/her to do things	He/she irritates me	I have to try not to criticise him/her	It's hard for us to agree on things	He/she does not appreciate what I do for him/her	He/she sometimes gets on my nerves	He/she does some things out of spite	When he/she constantly wants something from me, it annoys me	I have to insist that he/she behave differently	I'm often angry with him/her
4) I would feel bad for encouraging them to join me and try to think of ways to be more helpful.	0.09	0.033	0.12	0.039	0.053	-0.075	-0.034	-0.006	-0.045	0.05
5) I would feel bad about my role in this and think about what I could do to help them.	0.099	-0.009	$.176^{**}$	$.159^{*}$	0.108	-0.029	-0.028	-0.023	-0.048	0.018
6)I would wonder if there was something I missed or did wrong and try to make up for it.	0.09	0.027	$.224^{**}$	0.101	0.054	0.013	-0.101	-0.051	-0.05	-0.018

7) I would think about how they might be right, I could have done things differently and will try and change how I do things in future.	0.01	0.042	.143*	.161*	.159*	-0.037	0.1	-0.055	-0.067	-0.021

	CC items on FQ									
Guilt item on CARE	I have to keep asking him/her to do things	He/she irritates me	I have to try not to criticise him/her	It's hard for us to agree on things	He/she does not appreciate what I do for him/her	He/she sometimes gets on my nerves	He/she does some things out of spite	When he/she constantly wants something from me, it annoys me	I have to insist that he/she behave differently	I'm often angry with him/her
8) I would go over what I should do differently in order to prevent my relative's distress.	-0.045	-0.057	.207**	0.126	0.062	-0.038	-0.014	-.158*	-0.068	-0.039
9) I would think about where I went wrong and show I am sorry that I upset them.	0.072	0.009	.136*	.143*	.135*	-0.045	0.066	-0.083	-0.047	0.011
10) I would feel bad about this and would like to do something to make them feel better about it.	0.042	-0.062	.218**	0.113	0.005	-0.064	-0.001	-0.041	-0.035	-0.034

11) I would feel responsible for not supporting their independence more and think about how I could make up for it.	.137*	0.107	.305**	.225**	.225**	0.106	0.099	0.079	0.102	0.024

	CC items on FQ									
Guilt item on CARE	I have to keep asking him/her to do things	He/she irritates me	I have to try not to criticise him/her	It's hard for us to agree on things	He/she does not appreciate what I do for him/her	He/she sometimes gets on my nerves	He/she does some things out of spite	When he/she constantly wants something from me, it annoys me	I have to insist that he/she behave differently	I'm often angry with him/her
12) I would worry if this had damaged the trust in our relationship and think about how to repair this.	0.048	0.06	.183**	.227**	.149*	0.11	.166**	0.063	0.02	0.073
Shame items on CARE										
1) I would worry people think I am not doing a good job as a carer for my relative.	.261**	.152*	0.115	.288**	0.121	.176**	0.059	0.12	.178**	0.076

2) I would feel like I'm a failure.	.144*	.132*	.204**	.198**	.219**	0.102	0.035	0.086	0.081	.146*
3) I would feel like a bad person.	0.095	0.032	.217**	.216**	0.08	0.031	0.013	0.021	0.006	0.076
4) I would worry about what people think of me.	0.067	0.109	0.044	.236**	0.123	.160*	0.037	.177**	.177**	0.109

	CC items on FQ									
Shame item on CARE	I have to keep asking him/her to do things	He/she irritates me	I have to try not to criticise him/her	It's hard for us to agree on things	He/she does not appreciate what I do for him/her	He/she sometimes gets on my nerves	He/she does some things out of spite	When he/she constantly wants something from me, it annoys me	I have to insist that he/she behave differently	I'm often angry with him/her
5) I would feel like all eyes are on me.	0.094	.193**	.223**	.232**	.168**	.196**	0.094	0.123	0.089	.147*
6) I would feel as if I have failed.	.159*	0.094	.271**	.207**	.167**	0.111	-0.035	0.081	-0.019	0.081
7) I would feel like I'm not good enough and want to end the conversation.	0.017	.143*	.254**	.145*	.129*	.175**	0.118	.199**	0.034	.165*
8) I would feel small and avoid the topic.	0.084	.195**	.244**	.131*	.147*	.170**	0.083	.209**	0.126	.248**

9) I would think other families seem to manage without having these problems, why can’t we?	.213**	.367**	.213**	.277**	.195**	.286**	.139*	.313**	.193**	.270**
10) I would feel not good enough so avoid thinking about it	.183**	.186**	.280**	.175**	0.102	.159*	0.044	.141*	0.075	.198**

	CC items on FQ									
Shame item on CARE	I have to keep asking him/her to do things	He/she irritates me	I have to try not to criticise him/her	It's hard for us to agree on things	He/she does not appreciate what I do for him/her	He/she sometimes gets on my nerves	He/she does some things out of spite	When he/she constantly wants something from me, it annoys me	I have to insist that he/she behave differently	I'm often angry with him/her
11) I would think about how other people will judge me because of this.	.203**	.264**	.181**	.266**	.237**	.267**	0.048	.218**	.175**	.160*
12) I would feel bad that I couldn’t handle this on my own.	0.119	.167**	.224**	.287**	.171**	.139*	.139*	0.123	0.112	.229**

Blame items on CARE										
1) I would think they should be able to control their own actions.	0.067	.271**	.162*	.161*	.200**	.257**	.250**	.271**	.178**	.280**
2) I would raise the things that my relative is not doing to improve their situation.	0.125	.269**	.194**	.165*	0.112	.292**	.237**	.189**	.216**	.289**

	CC items on FQ									
Blame item on CARE	I have to keep asking him/her to do things	He/she irritates me	I have to try not to criticise him/her	It's hard for us to agree on things	He/she does not appreciate what I do for him/her	He/she sometimes gets on my nerves	He/she does some things out of spite	When he/she constantly wants something from me, it annoys me	I have to insist that he/she behave differently	I'm often angry with him/her
3) I would think they should look at their own role in their mental health difficulties.	.146*	.285**	.148*	.182**	.188**	.218**	.285**	.243**	.192**	.310**

4) I would think about how my relative should be taking more responsibility for their treatment so that they can be as well as possible.	.267**	.385**	.294**	.192**	.171**	.331**	.180**	.190**	.166*	.295**
5) I would think about how my relative didn't help themselves as much as they could have.	.195**	.308**	.200**	.195**	.242**	.318**	.319**	.265**	.226**	.366**
6) I would think they should have asked for help earlier if they were becoming this distressed.	.193**	.221**	.207**	0.076	.223**	.188**	.149*	.216**	.148*	.243**

	CC items on FQ									
Blame item on CARE	I have to keep asking him/her to do things	He/she irritates me	I have to try not to criticise him/her	It's hard for us to agree on things	He/she does not appreciate what I do for him/her	He/she sometimes gets on my nerves	He/she does some things out of spite	When he/she constantly wants something from me, it annoys me	I have to insist that he/she behave differently	I'm often angry with him/her

7) I would think about how they could have avoided this if they had just learned to look after themselves better.	.268**	.304**	.218**	.217**	0.117	.256**	.219**	.283**	.281**	.270**
8) I would think about how they need to learn to look after themselves better.	.223**	.295**	.220**	.141*	.143*	.283**	.173**	.338**	.258**	.355**
9) I would think they can do these things for themselves; they are just not doing what they should.	.306**	.342**	.262**	.167**	.210**	.330**	.146*	.300**	.249**	.256**
10) I would think my relative could have prevented this from happening and then I wouldn't have had to call.	.245**	.349**	.240**	.241**	.251**	.343**	.301**	.330**	.297**	.389**

	CC items on FQ

Blame item on CARE	I have to keep asking him/her to do things	He/she irritates me	I have to try not to criticise him/her	It's hard for us to agree on things	He/she does not appreciate what I do for him/her	He/she sometimes gets on my nerves	He/she does some things out of spite	When he/she constantly wants something from me, it annoys me	I have to insist that he/she behave differently	I'm often angry with him/her
11) I would think they shouldn’t be so sensitive and have better control over their emotions.	0.117	$.322^{**}$	$.206^{**}$	$.198^{**}$	$.160^{*}$	$.319^{**}$	$.267^{**}$	$.294^{**}$	$.239^{**}$	$.331^{**}$
12) I would think if they hadn’t behaved this way then I wouldn’t have become impatient.	$.168^{**}$	$.430^{**}$	$.367^{**}$	$.308^{**}$	$.292^{**}$	$.454^{**}$	$.428^{**}$	$.372^{**}$	$.324^{**}$	$.461^{**}$

Note. Externalised shame items are italicised.

Section Four - Ethics Proposal

Word count (excluding references, tables, and appendices): 2948

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Declarations of interest: none

Ethics Application Form

Faculty of Health and Medicine Research Ethics Committee (FHMREC)

Lancaster University

Application for Ethical Approval for Research

Title of Project: Care-givers Expressed Emotion: Validating a Measure of Guilt, Shame & Blame in a Care-giving Context

Name of applicant/researcher: Laura Noir

ACP ID number (if applicable)*: N/A **Funding source (if applicable):** N/A

Grant code (if applicable): N/A

***If your project has *not* been costed on ACP, you will also need to complete the Governance Checklist [link].**

Type of study

☐ Involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants. **Complete sections one, *two* and four of this form**

☒ Includes *direct* involvement by human subjects. **Complete sections one, *three* and four of this form**

SECTION ONE

1. Appointment/position held by applicant and Division within FHM trainee clinical psychologist

2. Contact information for applicant:

E-mail: l.noir@lancaster.ac.uk **Telephone**: XXXXXXXXXXX

Address:
Health Innovation One
Sir John Fisher Drive
Lancaster University
Lancaster
LA1 4AT

3. **Names and appointments of all members of the research team (including degree where applicable)**

Professor William Sellwood, Program Director, Faculty of Health and Medicine

3. If this is a student project, please indicate what type of project by marking the relevant box/deleting as appropriate: (please note that UG and taught masters projects should complete **FHMREC form UG-tPG**, following the procedures set out on the FHMREC website

PG Diploma ☐ Masters by research ☐ PhD Thesis ☐ PhD Pall. Care ☐

PhD Pub. Health ☐ PhD Org. Health & Well Being ☐ PhD Mental Health ☐ MD ☐

DClinPsy SRP ☐ [if SRP Service Evaluation, please also indicate here: ☐] DClinPsy Thesis ☒

4. Project supervisor(s), if different from applicant:
Professor Bill Sellwood (Program Director)

5. Appointment held by supervisor(s) and institution(s) where based (if applicable):

Professor William Sellwood, Program Director, Faculty of Health and Medicine, Health Innovation One, Sir John Fisher Drive, Lancaster University

SECTION TWO

Complete this section if your project involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants

1. Anticipated project dates (month and year)

Start date: End date:

2. Please state the aims and objectives of the project (no more than 150 words, in lay-person's language):

Data Management

For additional guidance on data management, please go to Research Data Management *webpage, or email the RDM support email:* rdm@lancaster.ac.uk

3. Please describe briefly the data or records to be studied, or the evaluation to be undertaken.

4a. How will any data or records be obtained?

4b. Will you be gathering data from websites, discussion forums and on-line 'chat-rooms' n o

4c. If yes, where relevant has permission / agreement been secured from the website moderator?

4d. If you are only using those sites that are open access and do not require registration, have you made your intentions clear to other site users?

4e. If no, please give your reasons

5. What plans are in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with General Data Protection Regulation (GDPR) and the (UK) Data Protection Act 2018.

6a. Is the secondary data you will be using in the public domain? n o

6b. If NO, please indicate the original purpose for which the data was collected, and comment on whether consent was gathered for additional later use of the data.

Please answer the following question *only* if you have not completed a Data Management Plan for an external funder

7a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

7b. Are there any restrictions on sharing your data?

8. Confidentiality and Anonymity

a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications? yes

b. How will the confidentiality and anonymity of participants who provided the original data be maintained?

9. What are the plans for dissemination of findings from the research?

10. What other ethical considerations (if any), not previously noted on this application, do you think there are in the proposed study? How will these issues be addressed?

SECTION THREE

Complete this section if your project includes *direct* involvement by human subjects

1. Summary of research protocol in lay terms (indicative maximum length 150 words):

Providing care for a relative with a long-term mental health difficulty can be a challenging and emotional experience. Pressures can build and manifest as being highly protective of the service user as well as critical and worried. Expressed emotion is a term used to describe these caring behaviours, which surprisingly are associated with worse outcomes for service users. Guilt and shame are thought to be related emotions, however few measurement tools show they can consistently and adequately measure shame and guilt in care-giving contexts.

To address this measurement issue, the current study aims to improve an existing scale to show adequate reliability (consistency) and validity (the structure aligns with current theory and is associated with other, gold standard, measures) properties. This scale, called the Care and Related Emotions (CARE) scale, measures shame, guilt and blame in a care-giving context and it is hoped a validated version will inform the design of effective familial interventions to reduce the risk of relapse.

To do this, a pilot version of the CARE scale will be administered to experts by experience and professionals. After making changes based on their feedback, a final version will be administered to carers along with other existing empirically-validated self-report measures of guilt and shame, followed by reliability and validity statistical analyses.

2. Anticipated project dates (month and year only)

Start date: November 2020 End date: July 2022

Data Collection and Management

For additional guidance on data management, please go to Research Data Management *webpage, or email the RDM support email:* rdm@lancaster.ac.uk

3. Please describe the sample of participants to be studied (including maximum & minimum number, age, gender):

This study will aim to recruit 320 participants and accept as a minimum threshold 160 participants. These figures are in keeping with best practice recommendations of recruiting 10 to 20 subjects per scale item (Anthoine, Moret, Regnault et al., 2014: reference below). Comrey & Lee (1992) suggest the total number of participants of must be above 100 to be acceptable, 200 to be considered “fair” or above 300 to be considered “good” and such guidelines are endorsed by establishments such as the American Psychiatric Association (APA: reference below).

Anthoine, E., Moret, L., Regnault, A. et al. (2014). Sample size used to validate a scale: a review of publications on newly-developed patient reported outcomes measures. *Health Qual Life Outcomes 12*, 2.

APA Handbook of Testing and Assessment in Psychology, Vol. 1: Test Theory and Testing and Assessment in Industrial and Organizational Psychology, edited by K. F. Geisinger, B. A. Bracken, J. F. Carlson, J.-I. C. Hansen, N. R. Kuncel, S. P. Reise, and M. C. Rodriguez (2013).

Comrey, A.L, Lee, H.B (1992). A First Course in Factor Analysis. 2nd edition. Lawrence Erlbaum Associates, Hillsdale, NJ.

Inclusion criteria:

Participants must be aged 18 or over.

Participants must provide care for someone diagnosed with a mental health difficulty (such as psychosis, bipolar, trauma responses or difficulties with eating, anxiety or mood), and who has been in contact with mental health services for more than six months. Engagement with mental health services will be self-reported.

Participants must be able to understand English in order to provide informed consent and understand the metrics presented.

Exclusion criteria:

To keep the focus on mental health difficulties, participants will not be able to take part in the study if their friend/relative does not have a long-term mental health difficulty. It will be explained in the participant information sheet that if their friend/relative is in contact with services for learning disabilities or developmental disorders or neurological conditions (such as dementia or traumatic brain injury) they should not proceed with the study. To clarify this information, participants will be asked to indicate if their friend/relative has been in contact with mental health services (with excluded services clearly identified) for more than six months in order to continue.

Participants that do not complete at least one of the measures of the study will be excluded.

4. How will participants be recruited and from where? Be as specific as possible. Ensure that you provide the full versions of all recruitment materials you intend to use with this application (eg adverts, flyers, posters).

Subject matter experts are individual who have professional experience or specific expertise working with people who provide care to individuals with a long-term mental health condition. Their expertise will be sought to provide insight on the administration and scoring procedures of the scale as well as item content and operational definitions. They will be recruited by inviting relevant members of the Faculty of Health and Medicine to participate or by contacting local services (e.g. eating disorder service) that work alongside carers.

Experiential experts are people who have personal experience of caring for someone who has a mental health difficulty. For the pilot version of this study, experiential experts will be recruited for cognitive interviews by approaching local mental health carer groups, who will be asked to forward our invitation to parties who may be interested. If this does not generate the expected response, recruitment will follow the same manner as participants (see below). Cognitive interviews will seek feedback on themes, item content, wording, questions and layout.

Participants will be recruited via third sector organisations and advertisements posted in public settings (such as carer organisations, websites, social media sites). Contacts in carer organisations will be emailed (see appendix) and requested to circulate study advertisements (see appendix) to known carers whose contact information they may retrieve from their address books or their email distribution lists or it may be shared via their social media accounts. The study advertisements will include the participant information sheet and survey link, as well as instructions on how to arrange a hard copy to be posted (see appendix).

5. Briefly describe your data collection and analysis methods, and the rationale for their use.

The Caring and Related Emotions (CARE) scale is a measure of guilt and shame that arises in a care-giving context. In an attempt to improve the reliability and validity of this scale the current study will have two data collection phases, as described below.

The first data collection phase will involve administering the existing version of the CARE scale (see appendix). This will function as a draft version and will initially be presented to subject matter experts to gain feedback on operational definitions and appropriateness of questions. Then, a small subsample of experiential experts will pilot the scale to gain their feedback on question items and to understand their cognitive reaction/interpretation as they use the test. These interviews will be audio recorded on Microsoft Teams and findings summarised in the final report. Following the feedback from this stage, changes will be made to the study and a final version of the CARE scale developed.

For the second stage, data will be quantitative and involve administering the final version of the CARE scale along with other items of the survey package (see measures section below). This data will be used to determine the reliability and validity of the study, using the following analysis methods:

Internal consistency: Several items per subscale will be included in the survey and the internal consistency between them determined using Cronbach's alpha.

Reliability: The final version of the CARE scale will be readministered to a subsample of a minimum 10 participants in the two weeks following the initial data collection. Correlational analysis will compare their initial scores (Time 1) scores of participants with their follow up (Time 2) scores.

Measurement error: calculate standard error of measurement from the square root of the mean square error in a repeated-measures analysis of variance (ANOVA).

Structural validity: perform exploratory factorial analysis to understand internal structure of the four scales.

Convergent validity: using correlational analysis compare CARE scale with a similar scale.

Discriminant validity: using correlational analysis compare CARE with a similar, but distinct scale.

Predictive validity: using correlational analysis, compare CARE with a related variable.

Measures:

The survey will include five questionnaires: a demographic questionnaire, a draft version of the Caring and Related Emotions (CARE) scale (Messham, 2014), the State Shame and Guilt Scale (Marshall, Saftner & Tangney, 1994), the Test of Self-Conscious Affect-3 (TOSCA-3; Tangney, Dearing, Wagner, & Gramzow, 2000) and the Family Questionnaire (FQ: Wiedemann, Rayki, Feinstein, & Hahlweg, 2002). Please see protocol for more information on these measures.

6. What plan is in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc.)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with General Data Protection Regulation (GDPR) and the (UK) Data Protection Act 2018.

Data storage: the data will be collected electronically and stored securely. Only researchers conducting this study will have access to it.

Responses from the survey package completed online will be collected via Qualtrics platform. Qualtrics uses Transport Layer Security encryption (also known as HTTPS) for all transmitted data. All electronic responses will be stored in the SPSS file format .sav and stored as per standard guidance of 10 years on the Lancaster University H drive. To uphold anonymity, the data accessible to the researcher and supervision team will not contain identifiable information.

Completed hard copies will be kept in a locked cabinet. Due to Covid-19 restricting access to campus, the locked cabinet will be at the researchers home address. Once scales have been coded and entered into the SPSS database, they will be destroyed. The hard copy version will not request identifiable information.

Cognitive interviews recorded on MS teams will initially be stored on One Drive until they are downloaded as soon as practical and stored on the Lancaster University H drive. All electronic files will only be accessed by myself and supervisors involved in the project.

Data security: The electronic anonymised data will be primarily stored on the university server. As I am not based full time at the university, access from home will be required. In these instances the data will be accessed via the VPN. If this is not available, data will stored on an encrypted and password protected USB drive. Following the data analysis period, the data will be securely transferred back to the university server for long term storage using One Drive.

Data stewardship: the data will be provided by Professor William Sellwood. Prof. Sellwood will remain the data steward and will be responsible for storing and deleting the data after I have finished the course in 2021.

The data will not be accessible to others outside of the applicant and project supervisors.

7. Will audio or video recording take place? ☐ no ☒ audio ☐ video

a. Please confirm that portable devices (laptop, USB drive etc) will be encrypted where they are used for identifiable data. If it is not possible to encrypt your portable devices, please comment on the steps you will take to protect the data.

No identifiable data however all recordings will be stored on an encrypted USB or the university H drive.

b What arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed?

All recordings will be stored on an encrypted USB or the university H drive and destroyed following data collection.

Please answer the following questions *only* if you have not completed a Data Management Plan for an external funder

8a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

Following the usual Lancaster University procedure of using PURE as the data repository.

8b. Are there any restrictions on sharing your data ?

Access will need to requested with permission granted on a case by case basis by the Faculty of Health and Medicine.

9. Consent

a. Will you take all necessary steps to obtain the voluntary and informed consent of the prospective participant(s) or, in the case of individual(s) not capable of giving informed consent, the permission of a legally authorised representative in accordance with applicable law? yes

b. Detail the procedure you will use for obtaining consent?

Consent will be obtained prior to participating in the study. After being presented with the participant information sheet, participants will asked to indicate on a cover sheet their consent before proceeding. The cover sheet that requests they acknowledge their consent could be either online or in paper form, depending on the participants' preference. To uphold anonymity, the form will only need to be ticked. The participant information sheet will include the principal investigators details as well as information about data collection, the use of the data for research purposes and the withdrawal process.

10. What discomfort (including psychological eg distressing or sensitive topics), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks. State the timescales within which participants may withdraw from the study, noting your reasons.

Although some participants may find it interesting to complete the survey package (see question 5 of this section or the protocol for a list of the scales included in the survey package), there is a risk that the process may be distressing for others.

Participants will be free to leave the study at any time, and will be reminded of this on the information sheet. Contact details of UK-based organisations will also be provided on the participant information sheet, along with links to an international directory of crisis services. As the data in anonymous and unidentifiable, after completion of the survey the participants will not be able to withdraw from the study.

11. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, noting the support available to you; counselling considerations arising from the sensitive or distressing nature of the research/topic; details of the lone worker plan you will follow, and the steps you will take).

Part of my recruitment strategy involves virtually meeting carers (with prior consent). It is unlikely but possible that I become distressed as a result of interviewing, in which case I will contact the project supervisor or a member of D. Clin. Psych clinical team. To preserve my privacy, only my university email address will be provided as contact information.

12. Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study.

While participants may find the research interesting, they are not expected to receive any direct benefits in taking part. However the study is likely to contribute to improved family interventions which may have an indirect impact on participants.

13. Details of any incentives/payments (including out-of-pocket expenses) made to participants:

None.

14. Confidentiality and Anonymity

a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications? yes

b. Please include details of how the confidentiality and anonymity of participants will be ensured, and the limits to confidentiality.

All survey data will be stored securely with access only permissible to the applicant and research supervisors. Any paper based copies of questionnaires will be kept in a locked cabinet and destroyed following electronic data entry.

All survey responses will be anonymous and the research team will not be to trace data back to any individual. Participants won't be asked to provide identifiable details, except for a small number of participants who opt to repeat the CARE scale at a later date (Time 2). For these participants, they will be asked to provide an email address to allow the Qualtrics system to email a unique URL that allows them to repeat the CARE scale at an appropriate time interval. To uphold anonymity the process of emailing URLs will be automated by Qualtrics so information visible to the researcher does not contain email addresses and cannot be linked to survey responses.

15. If relevant, describe the involvement of your target participant group in the *design and conduct* of your research.

I plan to meet with an identified carer's online via my university account on Microsoft Teams. This will be an opportunity to seek their feedback on the draft version of the measure as well as recruitment procedures and use this insight to refine or modify the measure and/or the study.

16. What are the plans for dissemination of findings from the research? If you are a student, include here your thesis.

Thesis submission

Publication in peer reviewed journal

Presentation at conferences

Feedback to participants via third sector care organisations and social media

17. What particular ethical considerations, not previously noted on this application, do you think there are in the proposed study? Are there any matters about which you wish to seek guidance from the FHMREC?

none.

SECTION FOUR: signature

Applicant electronic signature: Laura Noir Date 16/11/20

Student applicants: please tick to confirm that your supervisor has reviewed your application, and that they are happy for the application to proceed to ethical review ☐

Project Supervisor name (if applicable): Prof. William Sellwood Date application discussed 16/11/20

Submission Guidance

1. **Submit your FHMREC application by email to Becky Case (**fhmresearchsupport@lancaster.ac.uk) as two separate documents:
    - i. **FHMREC application form.**
      Before submitting, ensure all guidance comments are hidden by going into 'Review' in the menu above then choosing *show markup>balloons>show all revisions in line.*
    - ii. **Supporting materials.**
      Collate the **following materials for your study, if relevant, into a single word document:**
        - a. **Your full research proposal (background, literature review, methodology/methods, ethical considerations).**
        - b. Advertising materials (posters, e-mails)
        - c. Letters/emails of invitation to participate
        - d. Participant information sheets
        - e. Consent forms
        - f. Questionnaires, surveys, demographic sheets
        - g. Interview schedules, interview question guides, focus group scripts
        - h. Debriefing sheets, resource lists

   Please note that you DO NOT need to submit pre-existing measures or handbooks which support your work, but which cannot be amended following ethical review. These should simply be referred to in your application form.

2. Submission deadlines:
    - i. Projects including direct involvement of human subjects **[section 3 of the form was completed]**. The *electronic* version of your application should be submitted to Becky Case **by the committee deadline date.** Committee meeting dates and application submission dates are listed on the FHMREC website. Prior to the FHMREC meeting you may be contacted by the lead reviewer for further clarification of your application. Please ensure you are available to attend the committee meeting (either in person or via telephone) on the day that your application is considered, if required to do so.
    - ii. The following projects will normally be dealt with via chair's action, and may be submitted at any time. **[Section 3 of the form has *not* been completed, and is not required].** Those involving:
        - a. existing documents/data only;
        - b. the evaluation of an existing project with no direct contact with human participants;
        - c. service evaluations.

3. **You must submit this application from your Lancaster University email address, and copy your supervisor in to the email in which you submit this application**

Lancaster University

Applicant: Laura Noir
Supervisor: Bill Sellwood
Department: DHR
FHMREC Reference: FHMREC20063

25 February 2021

Re: FHMREC20063
Care-givers Expressed Emotion: Validating a Measure of Guilt, Shame & Blame in a Care-giving Context

Dear Laura,

Thank you for submitting your research ethics application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC)**. The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Email: fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

[redacted]

Dr. Elisabeth Suri-Payer
Research Ethics Officer, Secretary to FHMREC

Caregivers Expressed Emotion: Validating a Measure of Guilt, Shame and Blame in a Caregiving Context

Research Protocol

Providing care for relatives with a long-term mental health difficulty can be a challenging and emotional experience. Carers often feel pressure and unsuccessful coping can affect the care they give, which can lead to poor outcomes for their loved one. Expressed emotion (EE) is a construct to describe familial emotional climate, by capturing the emotional attitudes and behaviours towards the relative for whom they provide care.

Two key aspects of EE are, emotional over involvement (EOI) and critical comments (CC), with hostility and warmth considered other related but less relevant aspects (Barrowclough & Hooley, 2003). EOI describes overprotective or overly self-sacrificing behaviours that lead to intrusiveness, whereas CC refers to character-focused statements that convey disapproval of the service-users behaviour or hostile attitudes towards their traits or personality (Barrowclough & Hooley, 2003). Recently, the literature has moved towards understanding why some carers respond to relatives with emotional over-involvement or criticism, while others do not (Hooley, 2007).

Guilt and shame have been identified as predictors of EE with the transactional processes of EE been shown to evoke immense guilt and shame for carers (Hooley et al., 1995). Guilt and shame are self-conscious emotions with distinct profiles (Tangney & Dearing, 2002; Tracy and Robins, 2006). Guilt is attributing one’s actions to internal, unstable and controllable causes (I did a bad thing), while shame is attributing them to internal, stable and uncontrollable causes (I am a bad person; Tracy and Robins, 2006).

Both shame and guilt have a social function that drive behavioural responses. Shame is thought to shield from painful negative feelings by externalising blame onto others in the form of defensive criticism, hostility and aggression (Tracey and Robins, 2006). Shame is associated with both CC and EOI (Cherry et al., 2017), particularly where carers perceive their relative to have control over their mental health suggesting a relationship with blame (Barrowclough & Hooley, 2003; Messham, 2014). In contrast, guilt is thought to facilitate empathy and drive prosocial and reparative behaviours to alleviate their sense of responsibility for others' distress. Guilt may lead to the maintenance or development of EOI when a carer feels excessive responsibility for the difficulties or challenges of a service-user. In order to make amends they may engage in maladaptive help-giving leading to over-involvement (Wasserman et al., 2012).

Understanding EE at a process level is important as EE has been identified as a consistent and reliable predictor of relapse across many mental health difficulties (Butzlaff & Hooley, 1998; Haidl et al., 2018; Weintraub et al., 2017) and EE has also been associated with the increased levels of anxiety, depression and general psychological distress for carers (Kuipers et al., 2010; Perlick et al., 2007; Jansen et al., 2015). There is an argument that identifying shame and guilt in carers and understanding their role in EE will inform the design of improved familial interventions, interventions to support carers in their roles while safeguarding their wellbeing and their relatives' wellbeing (Cherry et al., 2018).

While there is a theoretical rationale for guilt and shame to inform interventions, the empirical evidence of a relationship with EOI and CC has shown inconsistencies. This may be due to limitations in current scales: often they measure general proneness or trait-like experiences of shame or guilt, which may limit their capacity to elicit associations in a caregiving context (Myers, 2010). Weisman de Mamani (2010) called for future research to determine if EE is associated with the shame and guilt elicited specifically in relation to a providing care for someone with a long term mental health condition. Cherry and colleagues' (2018) review suggested that this is indeed the case, however, scales used in the few studies examining this have not been evaluated in terms of reliability and validity and some of the studies included in the review were not in the form of peer-reviewed publications.

In an effort to address this measurement issue and capture the emotional experience of the caring role, the present study will standardise a set of scales to measure the instances of guilt and shame that arise when caring for people with a long-term mental health condition. With the Care and Related Emotions (CARE) scale, this study aims to develop an acceptable, reliable and valid self-report measure and contribute to our understanding of EE at the process level. To achieve this aim, the study will be undergo two phases. These will involve

1. Assessment of the acceptability, interpretability and appropriateness of the CARE scale with subject matter experts and experiential experts.
2. Determine if there is sufficient evidence of reliability and validity for the four CARE scales.

Method

Design

This study will allow us to empirically validate a new scales of guilt, shame and blame that is specific to the carer context. Considerations of reliability and validity are critical to the design of this study with Table 1 summarising the methodology to be engaged to determine if there is sufficient evidence of reliability and validity. This includes administering empirically validated self-report measures of guilt and shame alongside the new measure and readministering the new measure to a selection of participants.

As part of establishing interpretability and content validity, the main researcher will initially pilot the survey with subject matter experts and experiential experts. Subject matter experts will be approached to provide insight on the administration and scoring procedures of the scale, as well as item content and operational definitions. Cognitive interviews with experiential experts will test question clarity and consistency in respondents' interpretations of the questions. This will involve collecting verbal feedback to elicit their understanding of the question and the manner to which they came to their answer (DeMaio & Rothgeb 1996; Campanelli, 1997), using a semi-structured cognitive interview guide (e.g. Willis, 2014). Feedback will be processed and a final version of the scale developed.

Participants

Inclusion and Exclusion criteria

Participants will be adult carers of individuals with a long-term mental health difficulties. Participants will be aged over 18 and provide care for someone diagnosed with a long-term mental health difficulty, that is, someone who has been in contact with mental health services for more than six months. As expressed emotion has been shown to predict outcomes across diagnoses (Barrowclough & Hooley, 2003) and many cultures and ethnic groups (Weisman de Mamani et al., 2009), recruitment will not focus on particular mental health diagnoses or a particular geographical location.

Participants would be excluded if they are a carer for someone whose sole diagnosis was either neurological (such as acquired brain injury or vascular dementia) or a learning disability/developmental disorder.

Recruitment

We will aim to recruit 160-320 participants via third sector organisations, advertisements posted in public settings (such as websites, social media sites) and email to distribution lists. Contacts in carer organisations will be emailed (see appendix) and requested to distribute study advertisements (see appendix), which will include the participant information sheet and survey link, as well as instructions on how to arrange a hard copy to be posted (See Appendix). The online survey will initially display the participant information sheet, which participants will have to indicate they have read before being asked to provide their fully informed consent to participate. Once they have provided consent they will be able to proceed to the survey. Participants who wish to receive a hard copy of the survey will be asked to contact the main researcher via email or phone. If they are eligible they will be sent the participant information sheet and survey pack (that includes participant information sheet, consent form and questionnaires) with a pre-addressed return envelope.

Subject-matter Experts

Prior to recruitment of participants, a minimum of five subject matter experts will be approached to provide insight on the administration and scoring procedures of the scale as well as item content and operational definitions. Interviews will take place over the phone or online, will be audio recorded and take a maximum of 60 minutes. Subject matter experts will be recruited by contacting appropriate members of the Faculty of Health and Medicine at Lancaster University as well as local services who work with people who provide care to individuals with a long term mental health condition (e.g. eating disorder service). Five is considered an appropriate number to mitigate agreement by chance (Zamanzadeh et al., 2015).

Experiential Experts

A minimum of five experiential experts, that is adults who care for an individual with a long-term mental health difficulty, will be invited to participate in a cognitive interview to provide their experiential expertise on the scale. Experiential experts will be recruited by approaching local mental health carer groups. If this does not generate the expected response, recruitment will follow the same manner as participants. Interviews will seek their feedback on themes, item content, wording, questions and format. Delivered in a semi-structured format interviews will be audio recorded online or over the phone and take 60–90 minutes for each respondent.

Recruitment

Contacts in carer organisations will be emailed (see appendix) and requested to distribute an invitation for eligible participants to be involved in cognitive interviews. They will be presented with a participant information sheet and consent form. A minimum of five experts is considered appropriate to mitigate agreement by chance (Zamanzadeh et al., 2015).

Materials

The survey will include five questionnaires (submitted with application); a demographic questionnaire, a draft version of the Caring and Related Emotions (CARE) scale (Messham, 2014), the State Shame and Guilt Scale (Marshall, Saftner & Tangney, 1994), the Test of Self-Conscious Affect-3 (TOSCA-3; Tangney, Dearing, Wagner, & Gramzow, 2000) and the Family Questionnaire (FQ: Wiedemann, Rayki, Feinstein, & Hahlweg, 2002).

A demographic questionnaire will help understand the role of variables such as sociodemographic characteristics, such as age, sex, and socioeconomic status. Questions will also be asked about the person whom they provide care, such as their relationship to each other and further information on the mental health difficulty.

At present, the CARE scale (Messham, 2014) is a 16 item self-report questionnaire with four components that measure the role of guilt, shame, blame and externalisation in a caring context. The measure asks responders to rate on a 5-point Likert scale how they are likely to respond in 16 hypothetical caring scenarios. Previous studies have demonstrated good test-retest reliability and high internal consistency (Messham, 2014).

State Shame and Guilt Scale (SSGS: Marshall et al., 1994), is a 15 item self-report measure of shame, guilt and pride. Responses are on a 5-point Likert scale from 1 (not at all) to 5 (very strongly). Cronbach's alpha values for shame (0.86), guilt (0.90), and pride (0.87) have been shown to be highly acceptable and comparable with the original validation studies (Marshall et al., 1994). The questions will modified so as to remain relevant to a care context.

Guilt and shame proneness will be measured using Test of Self-Conscious Affect-3 (TOSCA-3; Tangney et al., 2000). TOSCA-3 is a 16 item self-report measure that asks participants to rate their shame and guilt responses to common guilt or shame inducing scenarios. Rated on a five-point Likert scales, high scores indicate high guilt or shame proneness. Based on previous versions of TOSCA, it is extensively validated, with acceptable internal consistency, test-retest reliability and predictive validity (Tangney, et al., 2000).

EE will be measured using the Family Questionnaire (FQ: Wiedemann et al., 2002). FQ is a brief, self-report measure that correlates highly with the widely recognised *gold standard* measure of EE, the Camberwell Family Interview (Leff & Vaughn, 1985). Participants rate 10 statements for each of the two sub-scales, CC and EOI, on 4-point Likert scales ranging from 1 (never/rarely) to 4 (very often). Previously demonstrated proficient test-retest reliability for CC ($r = .84$) and EOI ($r = .91$).

Data Collection

Data collection will involve two stages. Initially the draft version of the CARE scale will be presented to subject matter experts to gain feedback on operational definitions and appropriateness of questions. Then, a small subsample will pilot the scale to gain their feedback on question items and to understand their cognitive reaction/interpretation as they use the test. These interviews will be audio recorded on Microsoft Teams and findings summarised in the final report.

The second data collection stage will be quantitative and involve administering the final version of the scale along with other items of the survey package, as described earlier. While it is recommended to recruit 20 participants per survey item, a widely accepted rule of thumb (Nunnally, 1978, p. 421) recommends recruiting as low as ten participants per survey item. Empirical evidence suggests this is sufficient (Mundfrom, Shaw & Ke, 2005). Therefore, we will aim to recruit at least 160 participants. The survey will be hosted through Qualtrics Survey

Software, which automatically collates data to allow for exportation to MS Excel and SPSS software for cleaning and analysis. As internet access is a potential participation barrier, hard copy versions of the questionnaire are available to be posted to eligible participants, with an anonymous, pre-paid return envelope (pending funding approval).

Reliability and Validity

The terminology and definitions of reliability and validity lack standardisation across the literature. The COSMIN guidelines (Mokkink et al., 2010) sought international consensus in an attempt to clarify and standardise the terms to allow for increased uniformity in health measurement. Using the terminology and definitions of the COSMIN guidelines, Table 1 summarises the types of reliability and validity and how the current study seeks to address these. These terms reflect the five sources of validity evidence described in the Standards for Educational and Psychological Testing (AERA et al., 1999).

[Insert table 1]

Proposed Analysis

Data preparation

Prior to analysis, the data will be cleaned and participants who did not complete at least one measure will be removed from the analysis. A Missing Value Analysis will indicate the distribution of the missing data and if missing values need to be replaced.

Assumption testing

Then the data will be screened for normality and linearity (Field, 2017). Shapiro-Wilk provides increased power (Ghasemi & Zahediasl, 2012) however can increase the likelihood of a significant result in large sample sizes. Therefore histograms and P-P plot inspections will be performed.

Proposed Data Analysis

Internal consistency: measure the correlations of items on the same subscale, with Cronbach's alpha > 0.70 for each subscale considered sufficient evidence.

Reliability: using correlational analysis compare the Time 1 scores of participants with their Time 2 scores. Sufficient evidence of reliability will be gained if $r \geq 0.70$.

Measurement error: calculate standard error of measurement from the square root of the mean square error in a repeated-measures analysis of variance (ANOVA).

Structural validity: perform confirmatory factorial analysis, with sufficient evidence gained if comparative fit index or Tucker-Lewis index > 0.95.

Convergent validity: using correlational analysis compare CARE with SSGS, with sufficient evidence gained if $r \geq 0.70$.

Discriminant validity: using correlational analysis compare CARE with TOSCA-3, with sufficient evidence gained if $r < 0.70$ or $r <$ the convergent validity statistic.

Predictive validity: using correlational analysis, compare CARE with FQ with sufficient evidence gained if $r \geq 0.70$

Data Security & Storage

The survey will not ask for identifying information so at no time will this be stored with the data. Participants completing a hard copy will be asked to tick a consent form which will be kept in a locked cabinet, while the survey information will be added to the electronic database as soon as possible and then destroyed. Participants will be assigned a study ID, which a small subsample will need to provide if they complete the follow up (Time 2) study. The electronic data will be stored in the SPSS file format .sav as per standard guidance of 10 years on the Lancaster University H drive and only accessible by authorised individuals. Audio recordings from Microsoft Teams will be initially stored on One Drive and transferred to the Lancaster University H drive as soon as possible. Any identifiable information in the notes will be removed and replaced with pseudonyms or generic terms. As access from home will be required the data will be accessed via the VPN. If this is not available, data will stored on an encrypted and password protected USB drive. Following the data analysis period, the data will be securely transferred back to the university server for long term storage using One Drive. Data stewardship will be provided by my university supervisor, Professor William Sellwood. Prof Sellwood will remain the data steward and will be responsible for storing and deleting the data after I have finished the course in 2021.

Ethical concerns

Some participants may experience some distress discussing the shame and guilt associated with the caring context. While the pilot administration and cognitive interviews will be conducted by a trainee clinical psychologist (Laura Noir) who has experience working with service users and carers, the large proportion of respondents will be completing the self-report measure online. However, as a non-clinical population the risks are likely to be very low and to mitigate the impact participants will be made aware of possibility of risk in the participant information sheet with samples of sensitive questions provided.

Participants will be advised they are free to leave the study at any time and encouraged to contact their family doctor if they find they are persistently distressed by these issues. During the cognitive interview phase, before seeking their consent to proceed participants will be fully informed of the limits to confidentially. If risk issues were to arise, Laura Noir is trained in conducting brief risk assessments and will follow appropriate risk procedures, such as contacting a qualified clinical member of the research team. However, as previously mentioned this is not a clinical sample and anticipated risks are likely to be very low.

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Table 1

International consensus of types of reliability and validity as presented in COSMIN guidelines (Mokkink et al., 2010) with a description of the methodology to address each type.

Domain	Purpose	Method to address
Reliability		
Internal Consistency	Interrelatedness between items that measure different aspects of the same construct	Several items per subscale will be included in the survey and the statistical consistency between them determined using Chronbach's alpha.
Reliability	Responses show reproducibility over time	The CARE scale will be readministered to a subsample after two weeks.
Measurement Error	Changes in scores are not attributed to true differences.	The standard deviation of repeated measures analysis of variance for a single participant.
Validity		
Content Validity:		
Content Validity	Considers the appropriateness of questions, the operational definition employed and incorporates face validity.	Experiential experts will be identified to pilot the CARE scale and give cognitive interviews. In addition, feedback from subject matter experts will assist in generating a content validity index to understand the relevancy and clarity of items.
Construct Validity:		
Structural Validity	Degree to which existing subscales are factorially valid or reflect the theoretical dimensions of the construct.	Confirm existing subscales using exploratory factor analysis
Hypothesis Testing		
Convergent validity.	How close the new scale is related to other measures of the same construct	Compare with a measure of situational guilt and shame with the State Guilt & Shame Scale.
Discriminant validity.	Ability to distinguish between similar but distinct constructs	Distinguish from a measure of trait-like or proneness to guilt and shame, such as the (gold standard) Test of Self Conscious Affect-3 (TOSCA-3)
Cross-cultural Validity	How adequately a translated scale reflects the original version	The scale is not being translated however ethnicity information will be requested.

Criterion Validity:		
Predictive Validity	Ability to predict the outcome of another measure.	Compare with gold standard measure FQ
Responsiveness:		
Responsiveness	Ability of the scale to detect change over time	Requires longitudinal design which is beyond the scope of this study
Interpretability:		
Interpretability	Clinical meaning that can be inferred from scores	Seek feedback from subject matter experts on administration and scoring.

Appendices

Appendix A	Email to carer groups
Appendix B	Participant Information Sheet (paper version)
Appendix C	Participant Information Sheet (online version)
Appendix D	Consent form (online version)
Appendix E	Consent form (paper version)
Appendix F	Participation Advertisement
Appendix G	Cognitive Interview Guide
Appendix H	Demographics Questionnaire
Appendix I	Caring and Related Emotions Scale
Appendix J	State Shame and Guilt Scale
Appendix K	Test of Self Conscious Affect-3
Appendix L	Family Questionnaire

Appendix A – Email to carer groups

Dear (addressed by their name if known or the carer's group),

My name is Laura Noir, and I am trainee clinical psychologist based at Lancaster University. I am conducting a research project supervised by Professor Bill Sellwood. The project aims to understand more about how people feel in relation to their role as carer for a loved one with a long term mental health condition.

I have included further details about the study on the attached information sheet, which has been approved by Lancaster University's Ethics Committee.

Please could you read this information and consider circulating the details of the study to carers in your groups? Participation involves completing a questionnaire on the topic, which can be accessed here. If any interested carers prefer to complete hard copies, I will happily arrange this if you are able to provide a postal address.

If you have any further queries or concerns, please feel free to contact me using the details provided below.

Many thanks,
Laura

Laura Noir
Trainee Clinical Psychologist
l.noir@lancaster.ac.uk
Faculty of Health & Medicine
Health Innovation One,
Sir John Fisher Drive, Lancaster University

Appendix B - Participant Information Sheet (paper version)

Emotional Experiences of Carers for People Long Term Mental Health Difficulties

My name is Laura Noir and I would like to invite you to take part in a research study. Before you decide, you need to understand why the research is being done and what it involves for you. Please take the time to read the following information and talk to others if you wish.

This research project is part of the Doctorate in Clinical Psychology Programme at Lancaster University, Lancaster, United Kingdom.

What is the study about?
We are interested in knowing more about people who provide for a friend or relative who has a long-term mental health difficulty. Specifically, this study is about their emotional reactions and if these differ to other challenging and emotional experiences. We aim to present a measure that can specifically and consistently identify the unique emotional experiences that arise in care-giving scenarios.

For this study, we are specifically interested in the experiences of people who provide care for relatives or friends who experience a long-term mental health condition. If your loved one has been in contact with mental health services for more than six months, we would welcome your participation. Please note, for the purposes of this study services which provide support for people with learning disabilities, developmental conditions, or neurological conditions (such as dementia or an acquired brain injury) are not considered mental health services.

What will I be asked to do if I take part?
If you decide you would like to participate, will be asked to read and mark your initials on a form to give your consent. You will then be asked to complete a questionnaire, which should take around 20 minutes to complete.
These forms can be returned in the stamped addressed envelope.
There will be an opportunity to participate again with a shorter version of the questionnaire at a later stage.

Do I have to take part?
No. Your participation is entirely voluntary so the decision to take part is up to you. Even if you agree to take part, you can withdraw from the study at any point while you complete the questionnaire without giving a reason. However, once the questionnaires are complete you will not be able to withdraw consent as the study is anonymous and your specific information is not identifiable.

Will my data be identifiable?
No. Your responses are anonymous, meaning that data cannot be traced back to you. The data collected for this study will be stored securely and only my supervisors and I have access to the completed data. Copies of questionnaires completed by hand will be kept in a locked cabinet until the data is coded into an electronic version. After which, the hard copies will be destroyed securely.

What will happen to the results?

The results will be summarised, interpreted and reported as a thesis. They may later be submitted for publication in an academic journal.

Are there any risks?
There are no known risks to taking part in the research, although you will be answering questions on topics that are sensitive and you may experience some distress. For example, the survey will ask you rate the likelihood of your response to questions such as "your relative attempted to harm themselves…" or "your relative blames your family for his/her mental health difficulties…"

Should you become upset, you are free to leave the study at any time. If find you are persistently distressed by these issues, please contact your GP/family doctor for support.

Are there any benefits to taking part?
While you may find participating interesting, there are no direct benefits to taking part. Your answers will, however, help us improve future care and support for services users' and their friends and family.

Who has review the project?
This research has been reviewed by the Faculty of Health and Medicine Research Ethics Committee.

Where can I obtain further information about the study if I need it?
If you have any questions, please contact me, the principal investigator:
Laura Noir, l.noir@lancaster.ac.uk (professional telephone number to be included).

Complaints
If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Professor Roger Pickup Tel: +44 (0)1524 593746
Associate Dean for Research Email: r.pickup@lancaster.ac.uk

Thank you for taking the time to read this information sheet

Appendix C - Participant Information Sheet (online version)

Emotional Experiences of Carers for People with Long Term Mental Health Difficulties

My name is Laura Noir and I would like to invite you to take part in a research study. Before you decide, you need to understand why the research is being done and what it involves for you. Please take the time to read the following information and talk to others if you wish.

This research project is part of the Doctorate in Clinical Psychology Programme at Lancaster University, Lancaster, United Kingdom.

What is the study about?
We are interested in knowing more about people who provide for a friend or relative who has a long-term mental health difficulty. Specifically, this study is about their emotional reactions and if these differ to other challenging and emotional experiences. We aim to present a measure that can specifically and consistently identify the unique emotional experiences that arise in care-giving scenarios.

For this study, we are specifically interested in the experiences of people who provide care for relatives or friends who experience a long-term mental health condition. If your loved one has been in contact with mental health services for more than six months, we would welcome your participation. Please note, for the purposes of this study services which provide support for people with learning disabilities, developmental conditions, or neurological conditions (such as dementia or an acquired brain injury) are not considered mental health services.

What will I be asked to do if I take part?
If you decide you would like to participate, will be asked to read an online consent form. You will then be asked to complete a questionnaire, which should take around 20 minutes to complete. The questionnaires need to be completed in a single sitting, if you were to close the browser the answers would be lost.
Once you have completed the questionnaire, you have completed the study. At the end of the study you will be asked if you would like to complete a second shorter version of the questionnaire at a later date. This is so we can understand more about how responses change over time. If you choose to opt in to the second party of the study, you will be asked to provide your email address so a unique link to the shorter version of the study can be sent to you after an appropriate time interval. To uphold your anonymity this will be an automated process and the researchers will not be able to associate your questionnaire responses with your email address.

Do I have to take part?
No. Your participation is entirely voluntary so the decision to take part is up to you. Even if you agree to take part, you can withdraw from the study at any point while you complete the questionnaire without giving a reason. However, once the questionnaires are complete you will not be able to withdraw consent as the study is anonymous and your specific information is not identifiable.

Will my data be identifiable?
No. Your responses are anonymous, meaning that data cannot be traced back to you. The data collected for this study will be stored securely and only my supervisors and I have access to the

completed data. Copies of questionnaires completed by hand will be kept in a locked cabinet until the data is coded into an electronic version. After which, the hard copies will be destroyed securely.

What will happen to the results?
The results will be summarised, interpreted and reported as a thesis. They may later be submitted for publication in an academic journal.

Are there any risks?
There are no known risks to taking part in the research, although you will be answering questions on topics that are sensitive and you may experience some distress. For example, the survey will ask you rate the likelihood of your response to questions such as "your relative attempted to harm themselves…" or "your relative blames your family for his/her mental health difficulties…"

Should you become upset, you are free to leave the study at any time. If find you are persistently distressed by these issues, please contact your GP/family doctor for support.

Are there any benefits to taking part?
You may find participating interesting, there are no direct benefits to taking part. Your answers will, however, help us improve future care and support for services users and their friends and family.

Who has review the project?
This research has been reviewed by the Faculty of Health and Medicine Research Ethics Committee.

Where can I obtain further information about the study if I need it?
If you have any questions, please contact me, the principal investigator:
Laura Noir, l.noir@lancaster.ac.uk (professional telephone number to be included).

Complaints
If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Professor Roger Pickup Tel: +44 (0)1524 593746
Associate Dean for Research Email: r.pickup@lancaster.ac.uk

Thank you for taking the time to read this information section.

Appendix D - Consent form (online version)

By proceeding to the survey, you confirm that:

- You have read the information sheet and understand what is expected of you within this study
- You provide care for someone who has been in contact with mental health services for more than six months.
  Please note that for the purposes of this study, services which provide support for people with learning disabilities, developmental disorders or neurological conditions (such as dementia or acquired brain injuries) are not considered mental health services.
- You understand that any responses/information you give will remain anonymous
- You consent to this information being used for the purposes outlined in the participant information sheet
- You consent to Lancaster University keeping the anonymised data for a period of 10 years after the study has finished
- Your participation is voluntary and you are aware that you may choose to terminate your participation at any time for any reason
- By clicking on this link, you consent to taking part in this study

Appendix E – Consent form (paper version)

Consent Form

Title of Project: Emotional Experiences of Carers for People Long Term Mental Health Difficulties

By proceeding to the survey, you confirm that:	Please tick box
1. I confirm I have read the information sheet and understand what is expected of me within this study	
2. I confirm that I provide care for someone who has been in contact with mental health services for more than six months *For the purposes of this study, services which provide support for people with learning disabilities, developmental disorders or neurological conditions (such as dementia or acquired brain injuries) are not considered mental health services.*	
3. I understand that any responses/information I give will remain anonymous	
4. I consent to this information being used for the purposes outlined in the participant information sheet	
5. I consent to Lancaster University keeping the anonymised data for a period of 10 years after the study has finished	
6. My participation is voluntary and I am aware that I may choose to terminate my participation at any time for any reason	
7. By returning the completed surveys, I consent to taking part in this study	

Appendix F – Participation Advertisement

PARTICIPANTS NEEDED

You are invited to participate in our research

We are recruiting people who provide care to a friend or relative with a mental health difficulty, as we would like to understand more about *your* experience.

The research will explore the emotional experiences of caregiving for people with long-term mental health difficulties.

Click here to read more information about the study and make a decision to take part. Once you give your consent to proceed you will be presented with the questionnaire.

Any questions? Need a paper copy?
Please contact Laura Noir, Trainee Clinical Psychologist
l.noir@lancaster.ac.uk or (professional phone number to be added)

Appendix G – Cognitive Interview Guide

Cognitive Interview Guide

Study title: Emotional Experiences of Carers for People Long Term Mental Health Difficulties

- Welcome and thank participant for agreeing to meet
- Introduce self
- Read through the study's Participant Information Sheet
- Ask if they have any questions and answer where applicable.
- Outline interview procedure, duration and purposes of audio recording
- Explain limits to confidentiality
- Seek consent to proceed and audio record

The cognitive interview will proceed concurrently to completion of the demographics questionnaire and CARE scale, with appropriate cognitive probes used to generate more information from the participant.

Examples of cognitive probes presented by Willis (2015) include:

- Meaning-oriented probe: interpretation of specific terms
  e.g. "*What, to you, is 'a period of relapse'?"*
- Paraphrase of a question
  e.g. *"What is this question asking?"*
- Process-oriented probe
  e.g. *"How did you arrive at your answer?"*
- Evaluative probe
  e.g. *"Do you feel this question is easy or not easy to answer?"*
- Elaborative probes
  e.g. *"Why do you say that?"*
- Hypothetical probe
  e.g. "*What would it take for you to say that your relative is taking good care of themself?"*
- Recall probes
  e.g. *"What time period were you thinking about when answering that question?"*
- Exploratory probe
  e.g. *"Tell me more about that"*

To avoid fabricated responses when a participant isn't sure what to say, in introducing the cognitive interview I will outline there's no right or wrong answer, indicating that it's acceptable to not know how to answer a question.

In closing, I will ask if there is anything I haven't asked that seems relevant then seek feedback about the interview.

Appendix H - Demographics Questionnaire

The following questions ask for some demographic information about you and the person you care for. Please leave any questions you do not wish to answer blank.

About you:

1) What is your age?

2) What is your gender?

3) How would you describe your ethnicity?

4) How would you describe your current employment status (for example, in full-time employment, part- time employment, in full-time education)?

5) What is your relation to the person you provide care for (for example, mother, brother)

6) How long have you provided care to this person for, in years?

7) On average, how many hours per week are you in face to face care with the person (please do not include time spent asleep – Includes telephone and online contact eg skype)?

About the person you provide care for:

8) How old is the person that you provide care for?

9) What is their gender?

10) How would they describe their ethnicity?

11) What is their current employment status (for example, in full-time employment, part-time employment, in full-time education)?

12) What is the nature of their mental health issue/diagnosis? (e.g. psychosis, schizophrenia, anorexia, personality disorder, obsessive compulsive disorder, bipolar, anxiety, depression, etc)

13) How long have they been diagnosed with/experienced a mental health issue?

14) Do they have any other physical or mental health issues? If yes, please provide further information, if known.

Appendix I – Care and Related Emotions Scale

The Care Scale (Messham, 2014)

The CARE Questionnaire

Instructions

- Below is a list of events that may or may not have happened during the time you have cared for your relative.
- You should answer each question in relation to how you would respond *if the situation occurred today.*
- Each one has a list of statements that we would like you to rate for how likely you might think or feel in that way in response to the circumstances described. Please put a *circle* around each of your answers.
- There are no right or wrong answers. We just need to know how relatives in a caring role think and feel about these kind of events. Please be as honest as possible as this is most helpful for us.
- If a scenario has not happened, just make your best guess about how you would respond if it happened today.
- All your scores are anonymous.
- Please complete all ratings for the responses a) to d), for all of the questions.

In the following situations, how likely is it you would think or feel the following responses *(if the situation occurred today)…*

1) Your relative doesn't take their medication in the way prescribed, or not at all…		Not likely				Very likely
	a) I feel that to some extent this was down to me. I should have encouraged him/her to manage their medication.	1	2	3	4	5
	b) He/she should be taking more responsibility for their treatment so that they can be as well as possible.	1	2	3	4	5
	c) Many people don't take medication as prescribed, this may be because they don't like the side-effects.	1	2	3	4	5
	d) Others will see the impact of this and would think less well of us.	1	2	3	4	5
2) Your relative has experienced a period of relapse…		Not likely				Very likely
	a) Others will think less of us because of this situation.	1	2	3	4	5
	b) Good days and bad days are to be expected.	1	2	3	4	5
	c) I could have done something to help prevent this.	1	2	3	4	5
	d) He/she could have done something to avoid getting into this situation.	1	2	3	4	5
3) You have other regular commitments (such as work) alongside caring for your relative, and their mental health declines…		Not likely				Very likely
	a) I can't always be there for them to help stop this from happening, and I may not have been able to prevent it anyway.	1	2	3	4	5
	b) I am selfish for leaving them.	1	2	3	4	5
	b) I could have prevented this by spending more time with them.	1	2	3	4	5

	c) They need to learn to look after themselves.	1	2	3	4	5
4) Looking back to when your relative first experienced mental health difficulties…		Not likely				Very likely
	a) I thought about what others would think and avoided my friends.	1	2	3	4	5
	b) We've been really unlucky to have this happen to us.	1	2	3	4	5
	c) I should have done more to help them.	1	2	3	4	5
	d) He/she could have done more to prevent this from happening.	1	2	3	4	5
5) When your relative's diagnosis was first made…		Not likely				Very likely
	a) He/she could have done more to prevent this from happening.	1	2	3	4	5
	b) I didn't want to admit it to myself, or tell other people about it.	1	2	3	4	5
	c) It was a relief to know what was wrong.	1	2	3	4	5
	d) I was responsible for this happening.	1	2	3	4	5
6) Your relative has been acting unusually whilst in public with you (e.g shouting, agitated, responding to voices)…		Not likely				Very likely
	a) I am not a good enough carer to be able to help them properly.	1	2	3	4	5
	b) They should be able to control their own actions.	1	2	3	4	5
	c) They have a lot going on so it's understandable for them to be frustrated.	1	2	3	4	5
	d) I feel like I have done something to cause this.	1	2	3	4	5
7) There have been times when he/she has stayed in bed too long or lacked motivation…		Not likely				Very likely
	a) I should be doing more to help them.	1	2	3	4	5

	b) If they did more constructive things they would feel a lot better.	1	2	3	4	5
	c) This is part of their mental health difficulties and in some ways is to be expected.	1	2	3	4	5
	d) I felt like it's my fault for not supporting them enough to prevent this.	1	2	3	4	5
8) During a ward round, it hasn't been a positive week/month…		Not likely				Very likely
	a) My relative didn't try to help themselves as much as they could have.	1	2	3	4	5
	b) There is a lot going on for my relative, it's reasonable for them to have ups and downs.	1	2	3	4	5
	c) I would feel uncomfortable because I might have been able to do more to help.	1	2	3	4	5
	d) I think the staff and/or others will think that we are poor at coping.	1	2	3	4	5
9) Your relative attempted to harm themselves…		Not likely				Very likely
	a) I should have done more to prevent it from happening, I want to do more to make it up.	1	2	3	4	5
	b) I would feel ashamed.	1	2	3	4	5
	c) This can happen when people are really distressed, and there are people better placed to help if this happens.	1	2	3	4	5
	d) They should have asked for help if they were becoming this distressed.	1	2	3	4	5
10) Your relative blames your family for his/her mental health difficulties…		Not likely				Very likely
	a) They might have a point and perhaps I could have done things differently.	1	2	3	4	5
	b) I think they should look at their own role in their mental health difficulties.	1	2	3	4	5

	c) I would worry that people might think badly of us.	1	2	3	4	5
	d) They are just taking it out on us, it could just be a part of their mental	1	2	3	4	5
11) When talking to your friends, your relative's mental health difficulties come into the conversation…		Not likely				Very likely
	a) I explain that he/she could do more things to help themselves.	1	2	3	4	5
	b) I worry about what the other person is thinking and find I cut short conversations about this.	1	2	3	4	5
	c) I think I could have done things differently in order to prevent them.	1	2	3	4	5
	d) It is good to be able to explain it because it's not talked about enough.	1	2	3	4	5
12) People tend to be wary of your relative as he/she sometimes seems odd in public…		Not likely				Very likely
	a) I believe people judge us negatively.	1	2	3	4	5
	b) The public don't always understand what is going on for people with mental health difficulties and don't know how to respond.	1	2	3	4	5
	c) My relative can control this more, they just choose not to.	1	2	3	4	5
	d) I should be able to help them more.	1	2	3	4	5
13) During a conversation with your relative they became angry/upset…		Not likely				Very likely
	a) They shouldn't be so sensitive and have better control over their emotions.	1	2	3	4	5
	b) Other families seem to manage without having these problems, why can't we?	1	2	3	4	5
	c) They can become agitated/distressed quite easily because there are many things going on for them, including their mental health problem.	1	2	3	4	5

	d) I felt uneasy that I have said something to upset them.	1	2	3	4	5
14) You recognise that you've been less patient of your relative's mental health difficulties recently…		Not likely				Very likely
	a) It's natural to find it hard, and I need time off from this sometimes.	1	2	3	4	5
	b) If they hadn't have behaved this way then I wouldn't have been inpatient.	1	2	3	4	5
	c) I am concerned that if other people were to see these problems they would think negatively of me.	1	2	3	4	5
	d) I should do something to make them and me feel better about it.	1	2	3	4	5
15) Your relative has been struggling to take care of their own basic needs such as; eating properly, washing themselves and/or doing their laundry…		Not likely				Very likely
	a) I should have helped them be more independent.	1	2	3	4	5
	b) I think if people knew, they would think badly of us.	1	2	3	4	5
	c) Their mental health problems make even quite simple things rather difficult.	1	2	3	4	5
	d) He/she can do these things for themselves; they are just not doing what they should.	1	2	3	4	5
16) Your relative became unwell and you decided to ring services (e.g. community mental health team, police) to help…		Not likely				Very likely
	a) I would feel like I have let them down.	1	2	3	4	5
	b) My relative could have prevented this from happening and then I wouldn't have had to call.	1	2	3	4	5
	c) Other people will look down on me because I couldn't handle the situation and I called people that they don't think I should have.	1	2	3	4	5

	d) I know services can be helpful to support us and our relative.	1	2	3	4	5

Appendix J – State Shame and Guilt Scale

State Shame and Guilt Scale (SSGS)

The SSGS is a self-rating scale of in-the-moment (state) feelings of shame, and guilt experiences. Ten items (five for each of the two subscales) are rated on a 5-point scale Likert scale. The following are some statements which may or may not describe how you are feeling **right now**. Please rate each statement using the 5-point scale below. Remember to rate each statement based on how you are feeling **right at this moment**.

	Not feeling this way at all		Feeling this way somewhat		Feeling this way very strongly
1. I want to sink into the floor and disappear.	1	2	3	4	5
2. I feel remorse, regret.	1	2	3	4	5
3. I feel small.	1	2	3	4	5
4. I feel tension about something I have done.	1	2	3	4	5
5. I feel like I am a bad person.	1	2	3	4	5
6. I cannot stop thinking about something bad I have done.	1	2	3	4	5
7. I feel humiliated, disgraced.	1	2	3	4	5
8. I feel like apologizing, confessing.	1	2	3	4	5
9. I feel worthless, powerless.	1	2	3	4	5
10. I feel bad about something I have done.	1	2	3	4	5

Scoring <u>Each scale consists of 5 items:</u>
Shame - Items 1, 3, 5, 7, 9
Guilt - Items 2, 4, 6, 8, 10
All items are scored in a positive direction.

Total Shame (25 max): ________

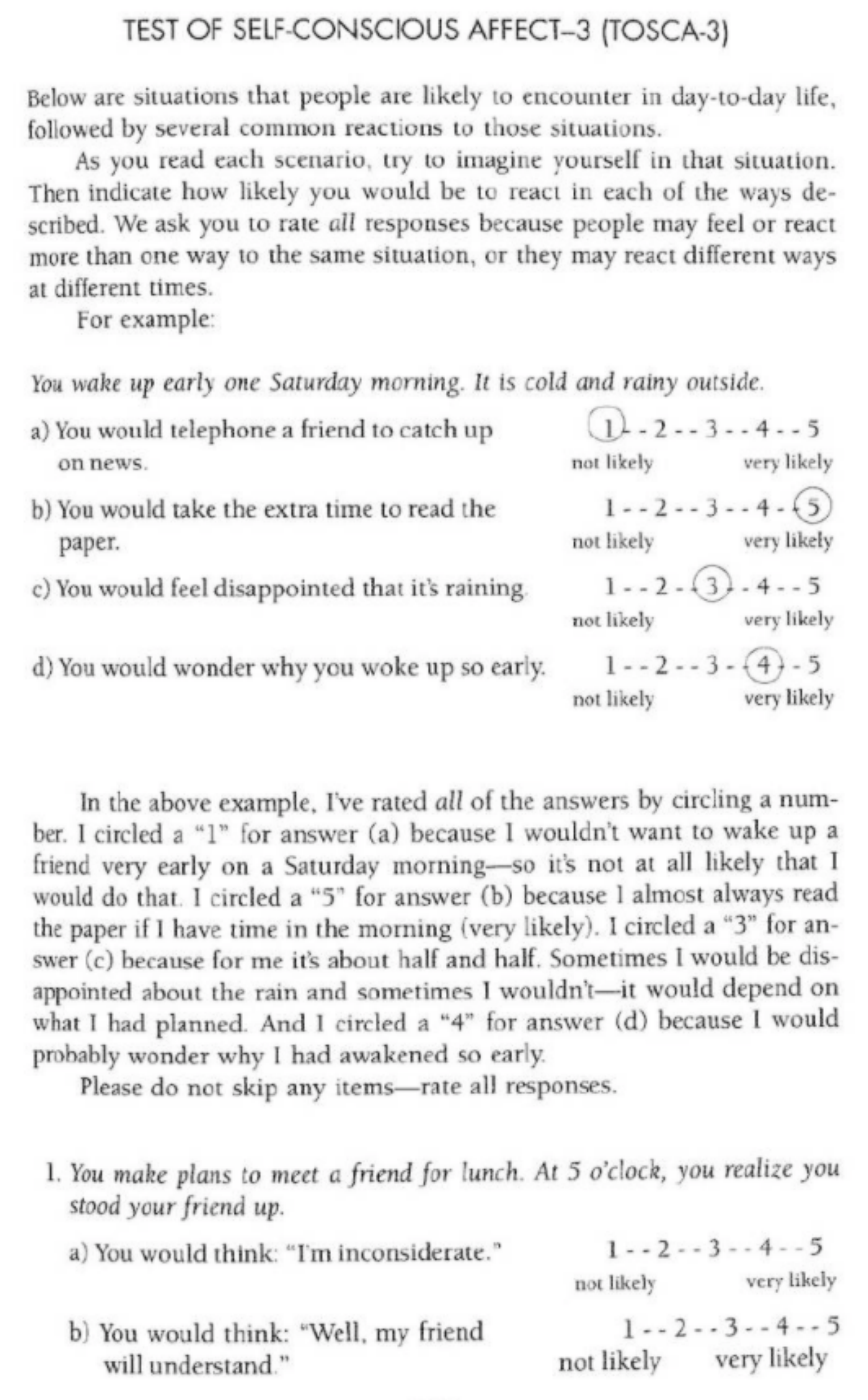
Total Guilt (25 max): ________

References

Marschall, D. E. (1996). Effects of induced shame on subsequent empathy and altruistic behavior. Unpublished master's thesis, George Mason University, Fairfax, VA.

Marschall, D. Saftner, J., & Tangney, J. P. (1994). <u>The State Shame and Guilt Scale</u>. George Mason University, Fairfax, VA.

Appendix K – TOSCA-3



TEST OF SELF-CONSCIOUS AFFECT–3 (TOSCA-3)

Below are situations that people are likely to encounter in day-to-day life, followed by several common reactions to those situations.

As you read each scenario, try to imagine yourself in that situation. Then indicate how likely you would be to react in each of the ways described. We ask you to rate *all* responses because people may feel or react more than one way to the same situation, or they may react different ways at different times.

For example:

You wake up early one Saturday morning. It is cold and rainy outside.

a) You would telephone a friend to catch up on news. [✓ 1] - - 2 - - 3 - - 4 - - 5 (not likely … very likely)

b) You would take the extra time to read the paper. 1 - - 2 - - 3 - - 4 - - [✓ 5] (not likely … very likely)

c) You would feel disappointed that it's raining. 1 - - 2 - - [✓ 3] - - 4 - - 5 (not likely … very likely)

d) You would wonder why you woke up so early. 1 - - 2 - - 3 - - [✓ 4] - - 5 (not likely … very likely)

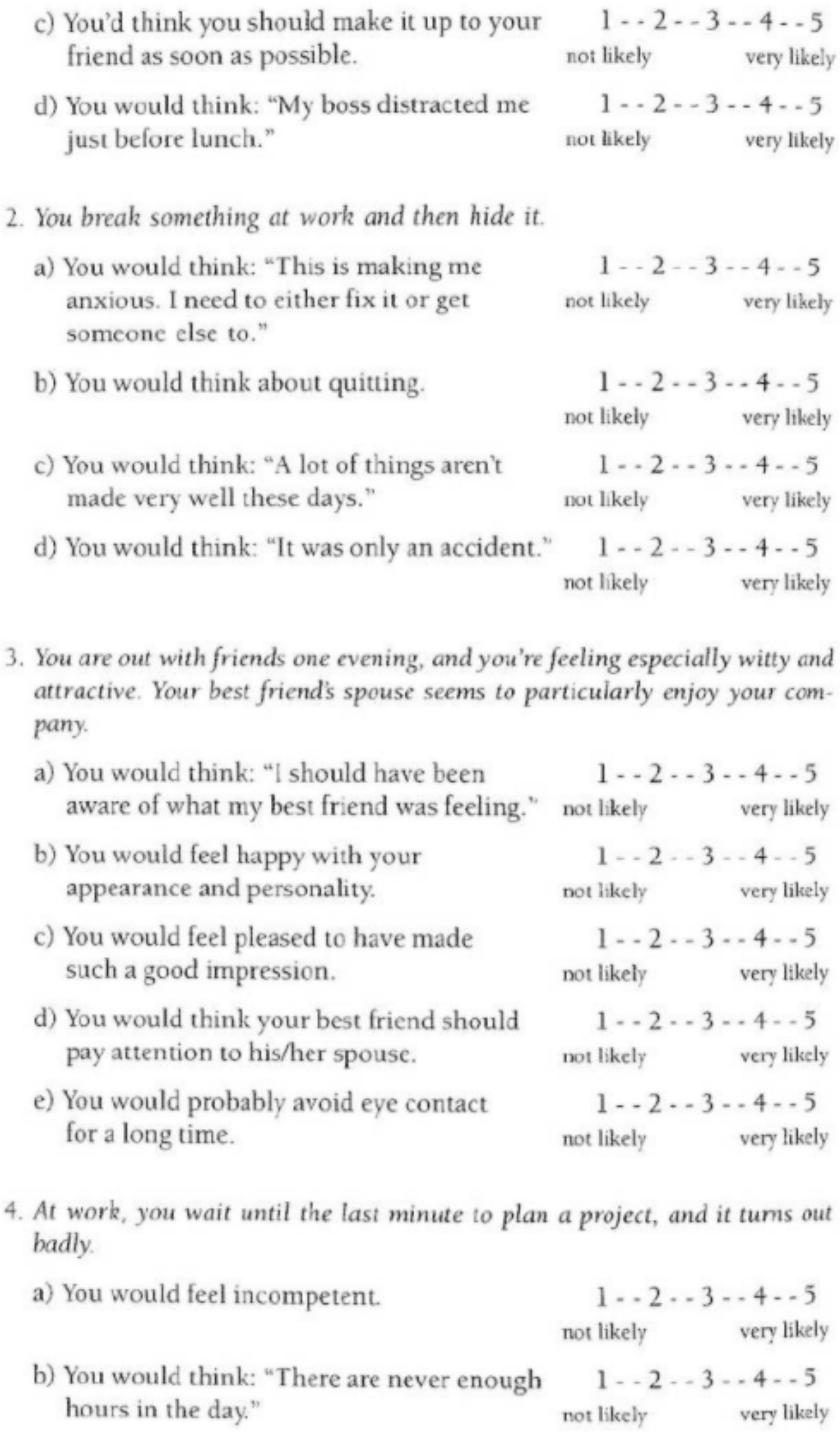
In the above example, I've rated *all* of the answers by circling a number. I circled a "1" for answer (a) because I wouldn't want to wake up a friend very early on a Saturday morning—so it's not at all likely that I would do that. I circled a "5" for answer (b) because I almost always read the paper if I have time in the morning (very likely). I circled a "3" for answer (c) because for me it's about half and half. Sometimes I would be disappointed about the rain and sometimes I wouldn't—it would depend on what I had planned. And I circled a "4" for answer (d) because I would probably wonder why I had awakened so early.

Please do not skip any items—rate all responses.

1. *You make plans to meet a friend for lunch. At 5 o'clock, you realize you stood your friend up.*

   a) You would think: "I'm inconsiderate." 1 - - 2 - - 3 - - 4 - - 5 (not likely … very likely)

   b) You would think: "Well, my friend will understand." 1 - - 2 - - 3 - - 4 - - 5 (not likely … very likely)



c) You'd think you should make it up to your friend as soon as possible.	1 - - 2 - - 3 - - 4 - - 5 not likely very likely
d) You would think: "My boss distracted me just before lunch."	1 - - 2 - - 3 - - 4 - - 5 not likely very likely

2. *You break something at work and then hide it.*

a) You would think: "This is making me anxious. I need to either fix it or get someone else to."	1 - - 2 - - 3 - - 4 - - 5 not likely very likely
b) You would think about quitting.	1 - - 2 - - 3 - - 4 - - 5 not likely very likely
c) You would think: "A lot of things aren't made very well these days."	1 - - 2 - - 3 - - 4 - - 5 not likely very likely
d) You would think: "It was only an accident."	1 - - 2 - - 3 - - 4 - - 5 not likely very likely

3. *You are out with friends one evening, and you're feeling especially witty and attractive. Your best friend's spouse seems to particularly enjoy your company.*

a) You would think: "I should have been aware of what my best friend was feeling."	1 - - 2 - - 3 - - 4 - - 5 not likely very likely
b) You would feel happy with your appearance and personality.	1 - - 2 - - 3 - - 4 - - 5 not likely very likely
c) You would feel pleased to have made such a good impression.	1 - - 2 - - 3 - - 4 - - 5 not likely very likely
d) You would think your best friend should pay attention to his/her spouse.	1 - - 2 - - 3 - - 4 - - 5 not likely very likely
e) You would probably avoid eye contact for a long time.	1 - - 2 - - 3 - - 4 - - 5 not likely very likely

4. *At work, you wait until the last minute to plan a project, and it turns out badly.*

a) You would feel incompetent.	1 - - 2 - - 3 - - 4 - - 5 not likely very likely
b) You would think: "There are never enough hours in the day."	1 - - 2 - - 3 - - 4 - - 5 not likely very likely

c) You would feel: "I deserve to be reprimanded for mismanaging the project."
1 - - 2 - - 3 - - 4 - - 5
not likely very likely

d) You would think: "What's done is done."
1 - - 2 - - 3 - - 4 - - 5
not likely very likely

5. *You make a mistake at work and find out a coworker is blamed for the error.*

a) You would think the company did not like the coworker.
1 - - 2 - - 3 - - 4 - - 5
not likely very likely

b) You would think: "Life is not fair."
1 - - 2 - - 3 - - 4 - - 5
not likely very likely

c) You would keep quiet and avoid the coworker.
1 - - 2 - - 3 - - 4 - - 5
not likely very likely

d) You would feel unhappy and eager to correct the situation.
1 - - 2 - - 3 - - 4 - - 5
not likely very likely

6. *For several days you put off making a difficult phone call. At the last minute you make the call and are able to manipulate the conversation so that all goes well.*

a) You would think: "I guess I'm more persuasive than I thought."
1 - - 2 - - 3 - - 4 - - 5
not likely very likely

b) You would regret that you put it off.
1 - - 2 - - 3 - - 4 - - 5
not likely very likely

c) You would feel like a coward.
1 - - 2 - - 3 - - 4 - - 5
not likely very likely

d) You would think: "I did a good job."
1 - - 2 - - 3 - - 4 - - 5
not likely very likely

e) You would think you shouldn't have to make calls you feel pressured into.
1 - - 2 - - 3 - - 4 - - 5
not likely very likely

7. *While playing around, you throw a ball and it hits your friend in the face.*

a) You would feel inadequate that you can't even throw a ball.
1 - - 2 - - 3 - - 4 - - 5
not likely very likely

b) You would think maybe your friend needs more practice at catching.
1 - - 2 - - 3 - - 4 - - 5
not likely very likely

c) You would think: "It was just an accident." 1 - - 2 - - 3 - - 4 - - 5
not likely very likely

d) You would apologize and make sure your friend feels better. 1 - - 2 - - 3 - - 4 - - 5
not likely very likely

8\. *You have recently moved away from your family, and everyone has been very helpful. A few times you needed to borrow money, but you paid it back as soon as you could.*

a) You would feel immature. 1 - - 2 - - 3 - - 4 - - 5
not likely very likely

b) You would think: "I sure ran into some bad luck." 1 - - 2 - - 3 - - 4 - - 5
not likely very likely

c) You would return the favor as quickly as you could. 1 - - 2 - - 3 - - 4 - - 5
not likely very likely

d) You would think: "I am a trustworthy person." 1 - - 2 - - 3 - - 4 - - 5
not likely very likely

e) You would be proud that you repaid your debts. 1 - - 2 - - 3 - - 4 - - 5
not likely very likely

9\. *You are driving down the road, and you hit a small animal.*

a) You would think the animal shouldn't have been on the road. 1 - - 2 - - 3 - - 4 - - 5
not likely very likely

b) You would think: "I'm terrible." 1 - - 2 - - 3 - - 4 - - 5
not likely very likely

c) You would feel: "Well, it was an accident." 1 - - 2 - - 3 - - 4 - - 5
not likely very likely

d) You'd feel bad you hadn't been more alert driving down the road. 1 - - 2 - - 3 - - 4 - - 5
not likely very likely

10\. *You walk out of an exam thinking you did extremely well. Then you find out you did poorly.*

a) You would think: "Well, it's just a test." 1 - - 2 - - 3 - - 4 - - 5
not likely very likely

b) You would think: "The instructor doesn't like me." 1 - - 2 - - 3 - - 4 - - 5
not likely very likely

c) You would think: "I should have studied harder."	1 - - 2 - - 3 - - 4 - - 5 not likely very likely
d) You would feel stupid.	1 - - 2 - - 3 - - 4 - - 5 not likely very likely

11. *You and a group of coworkers worked very hard on a project. Your boss singles you out for a bonus because the project was such a success.*

a) You would feel the boss is rather short-sighted.	1 - - 2 - - 3 - - 4 - - 5 not likely very likely
b) You would feel alone and apart from your colleagues.	1 - - 2 - - 3 - - 4 - - 5 not likely very likely
c) You would feel your hard work had paid off.	1 - - 2 - - 3 - - 4 - - 5 not likely very likely
d) You would feel competent and proud of yourself.	1 - - 2 - - 3 - - 4 - - 5 not likely very likely
e) You would feel you should not accept it.	1 - - 2 - - 3 - - 4 - - 5 not likely very likely

12. *While out with a group of friends, you make fun of a friend who's not there.*

a) You would think: "It was all in fun; it's harmless."	1 - - 2 - - 3 - - 4 - - 5 not likely very likely
b) You would feel small . . . like a rat.	1 - - 2 - - 3 - - 4 - - 5 not likely very likely
c) You would think that perhaps that friend should have been there to defend him/herself.	1 - - 2 - - 3 - - 4 - - 5 not likely very likely
d) You would apologize and talk about that person's good points.	1 - - 2 - - 3 - - 4 - - 5 not likely very likely

13. *You make a big mistake on an important project at work. People were depending on you, and your boss criticizes you.*

a) You would think your boss should have been more clear about what was expected of you.	1 - - 2 - - 3 - - 4 - - 5 not likely very likely
b) You would feel like you wanted to hide.	1 - - 2 - - 3 - - 4 - - 5 not likely very likely

c) You would think: "I should have recognized the problem and done a better job." 1 - - 2 - - 3 - - 4 - - 5
not likely very likely

d) You would think: "Well, nobody's perfect." 1 - - 2 - - 3 - - 4 - - 5
not likely very likely

14. *You volunteer to help with the local Special Olympics for handicapped children. It turns out to be frustrating and time-consuming work. You think seriously about quitting, but then you see how happy the kids are.*

a) You would feel selfish, and you'd think you are basically lazy. 1 - - 2 - - 3 - - 4 - - 5
not likely very likely

b) You would feel you were forced into doing something you did not want to do. 1 - - 2 - - 3 - - 4 - - 5
not likely very likely

c) You would think: "I should be more concerned about people who are less fortunate." 1 - - 2 - - 3 - - 4 - - 5
not likely very likely

d) You would feel great that you had helped others. 1 - - 2 - - 3 - - 4 - - 5
not likely very likely

e) You would feel very satisfied with yourself. 1 - - 2 - - 3 - - 4 - - 5
not likely very likely

15. *You are taking care of your friend's dog while your friend is on vacation, and the dog runs away.*

a) You would think, "I am irresponsible and incompetent." 1 - - 2 - - 3 - - 4 - - 5
not likely very likely

b) You would think your friend must not take very good care of the dog or it wouldn't have run away. 1 - - 2 - - 3 - - 4 - - 5
not likely very likely

c) You would vow to be more careful next time. 1 - - 2 - - 3 - - 4 - - 5
not likely very likely

d) You would think your friend could just get a new dog. 1 - - 2 - - 3 - - 4 - - 5
not likely very likely

16. *You attend your coworker's housewarming party and you spill red wine on a new cream-colored carpet, but you think no one notices.*

a) You think your coworker should have expected some accidents at such a big party. 1 - - 2 - - 3 - - 4 - - 5
not likely very likely

b) You would stay late to help clean up the stain after the party. 1 - - 2 - - 3 - - 4 - - 5 not likely very likely

c) You would wish you were anywhere but at the party. 1 - - 2 - - 3 - - 4 - - 5 not likely very likely

d) You would wonder why your coworker chose to serve red wine with the new light carpet. 1 - - 2 - - 3 - - 4 - - 5 not likely very likely

We are now recommending the use of the TOSCA-3 in place of the TOSCA and TOSCA-2. The TOCSA-3 is composed of 11 negative and 5 positive scenarios yielding indices of Shame-Proneness, Guilt-Proneness, Externalization, Detachment/Unconcern, Alpha Pride, and Beta Pride.

The majority of TOSCA-3 items are identical to the original TOSCA (Tangney, Wagner, & Gramzow, 1989). TOSCA scenarios were drawn from written accounts of personal shame, guilt, and pride experiences provided by a sample of several hundred college students and noncollege adults. The responses were drawn from a much larger pool of affective, cognitive, and behavioral responses provided by a second sample of adults.

In a subsequent revision, the TOSCA-2 (Tangney, Ferguson, Wagner, Crowley, & Gramzow, 1996), an experimental "Maladaptive Guilt" scale was introduced. In addition, we added two new scenarios and deleted the "Dieting" scenario, owing to concerns about gender bias. This most recent version of our measure, the TOSCA-3 (Tangney, Dearing, Wagner, & Gramzow, 2000), eliminates the Maladaptive Guilt items because analyses have raised serious questions about the discriminant validity of this scale. (The Shame and Maladaptive Guilt scales correlate about .79.)

As a new feature, the TOSCA-3 provides the option of a short version, which drops positive scenarios (and therefore eliminates the Pride scales). In a recent study, short versions of the TOSCA-3 Shame and Guilt scales correlated .94 and .93, respectively with their corresponding full length versions, thus supporting the utility of the abbreviated form.

Scoring for the TOSCA-3*:

1. (Negative Scenario)
   a) Shame
   b) Detached
   c) Guilt
   d) Externalization
2. (Negative Scenario)
   a) Guilt

9. (Negative Scenario)
   a) Externalization
   b) Shame
   c) Detached
   d) Guilt
10. (Negative Scenario)
   a) Detached

  - b) Shame
  - c) Externalization
  - d) Detached

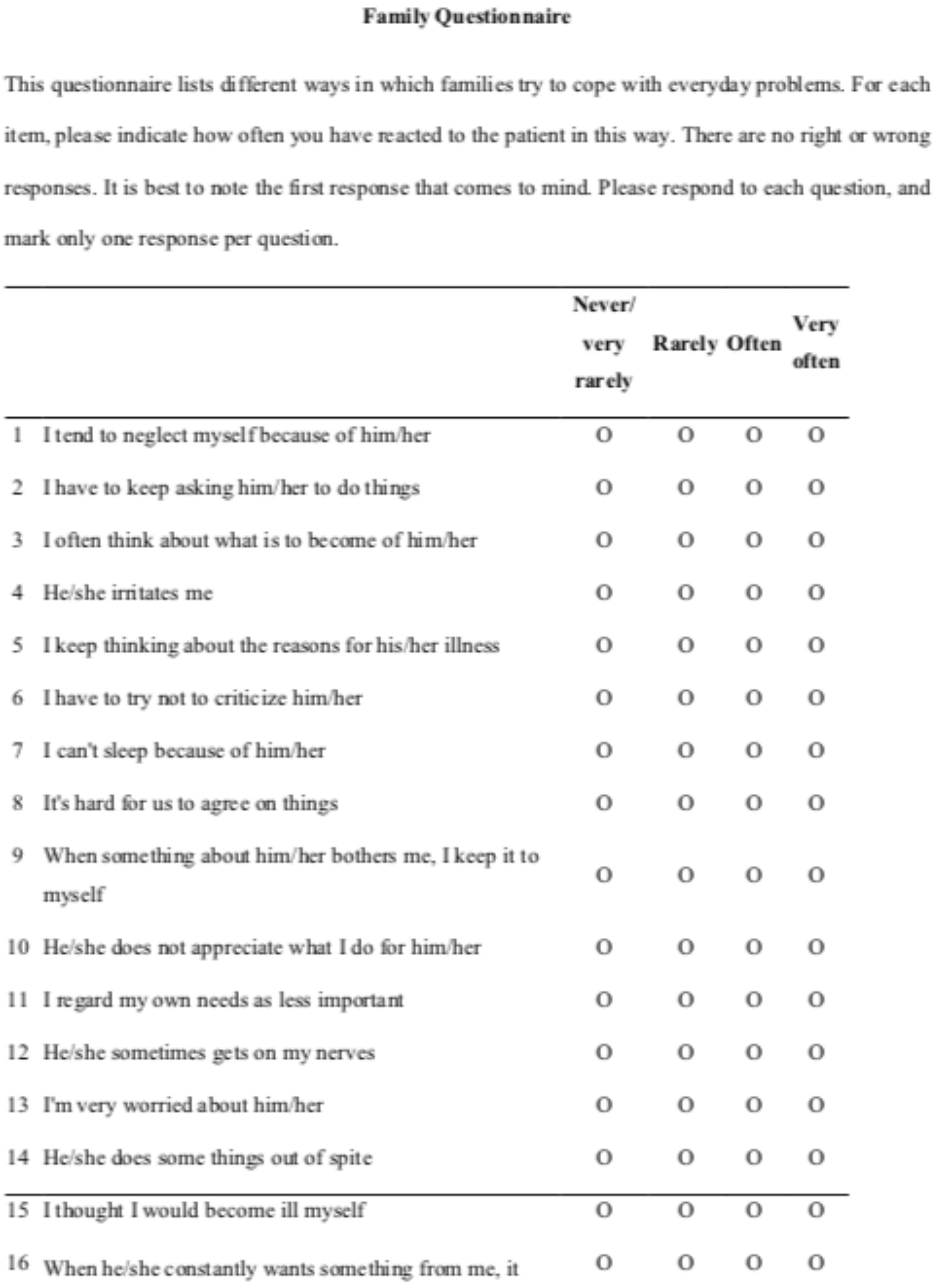
3. (Positive Scenario)
   - a) Guilt
   - b) Alpha Pride
   - c) Beta Pride
   - d) Externalization
   - e) Shame
4. (Negative Scenario)
   - a) Shame
   - b) Externalization
   - c) Guilt
   - d) Detached
5. (Negative Scenario)
   - a) Externalization
   - b) Detached
   - c) Shame
   - d) Guilt
6. (Positive Scenario)
   - a) Alpha Pride
   - b) Guilt
   - c) Shame
   - d) Beta Pride
   - e) Externalization
7. (Negative Scenario)
   - a) Shame
   - b) Externalization
   - c) Detached
   - d) Guilt
8. (Positive Scenario)
   - a) Shame
   - b) Externalization
   - c) Guilt
   - d) Alpha Pride
   - e) Beta Pride

  - b) Externalization
  - c) Guilt
  - d) Shame

11. (Positive Scenario)
    - a) Externalization
    - b) Shame
    - c) Beta Pride
    - d) Alpha Pride
    - e) Guilt
12. (Negative Scenario)
    - a) Detached
    - b) Shame
    - c) Externalization
    - d) Guilt
13. (Negative Scenario)
    - a) Externalization
    - b) Shame
    - c) Guilt
    - d) Detached
14. (Positive Scenario)
    - a) Shame
    - b) Externalization
    - c) Guilt
    - d) Beta Pride
    - e) Alpha Pride
15. (Negative Scenario)
    - a) Shame
    - b) Externalization
    - c) Guilt
    - d) Detached
16. (Negative Scenario)
    - a) Detached
    - b) Guilt
    - c) Shame
    - d) Externalization

A short version of the TOSCA-3 may be created by dropping the positive scenarios.

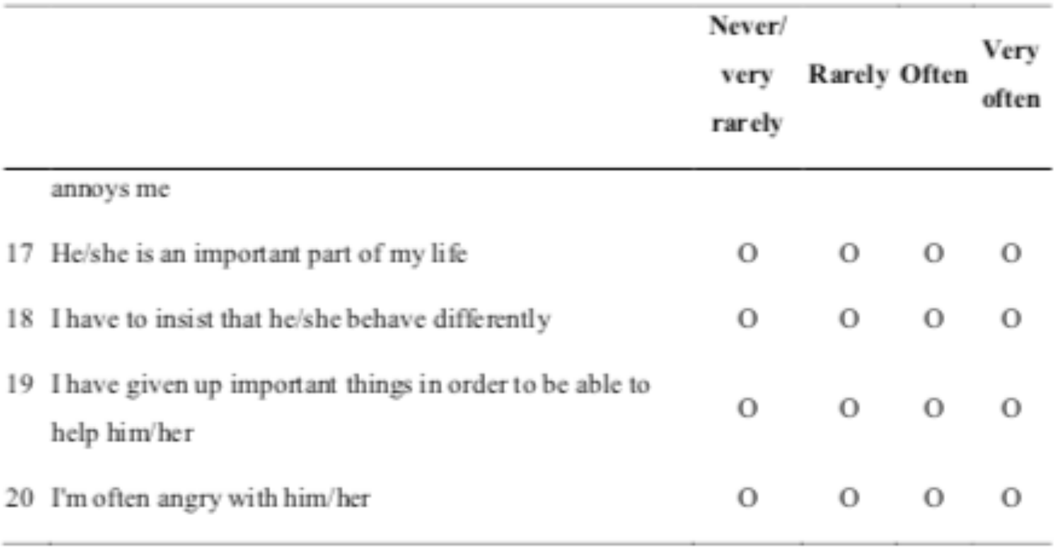
Appendix L – Family Questionnaire



Family Questionnaire

This questionnaire lists different ways in which families try to cope with everyday problems. For each item, please indicate how often you have reacted to the patient in this way. There are no right or wrong responses. It is best to note the first response that comes to mind. Please respond to each question, and mark only one response per question.

		Never/ very rarely	Rarely	Often	Very often
1	I tend to neglect myself because of him/her	○	○	○	○
2	I have to keep asking him/her to do things	○	○	○	○
3	I often think about what is to become of him/her	○	○	○	○
4	He/she irritates me	○	○	○	○
5	I keep thinking about the reasons for his/her illness	○	○	○	○
6	I have to try not to criticize him/her	○	○	○	○
7	I can't sleep because of him/her	○	○	○	○
8	It's hard for us to agree on things	○	○	○	○
9	When something about him/her bothers me, I keep it to myself	○	○	○	○
10	He/she does not appreciate what I do for him/her	○	○	○	○
11	I regard my own needs as less important	○	○	○	○
12	He/she sometimes gets on my nerves	○	○	○	○
13	I'm very worried about him/her	○	○	○	○
14	He/she does some things out of spite	○	○	○	○
15	I thought I would become ill myself	○	○	○	○
16	When he/she constantly wants something from me, it	○	○	○	○



		Never/ very rarely	**Rarely**	**Often**	**Very often**
	annoys me				
17	He/she is an important part of my life	○	○	○	○
18	I have to insist that he/she behave differently	○	○	○	○
19	I have given up important things in order to be able to help him/her	○	○	○	○
20	I'm often angry with him/her	○	○	○	○